

**EXPLANATORY MODELS OF CERVICAL CANCER AMONG WOMEN ACCESSING
CERVICAL CANCER DISEASE CARE AND TREATMENT SERVICES IN LUSAKA,
ZAMBIA**

BY

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A dissertation submitted to the University of Zambia in partial fulfillment of the requirements of
the degree of Masters in Public Health (Health Promotion)

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DECLARATION

I, Jane Matambo declare that this dissertation submitted to the University of Zambia as partial fulfillment of the award of the degree of Master of Public Health (Health Promotion and Education) is my own work and has not been submitted either wholly or in part for another degree to this University or any other Institute of Higher Education.

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ABSTRACT

Greater than 20% of the world's annual deaths from cervical cancer occur in sub-Saharan African countries, like Zambia, where cervical cancer is the most common malignancy and the leading cause of cancer-related deaths. Despite the disease being highly preventable with screening and early detection, no more than 5% of women in these settings are screened for cervical cancer. Lay perspectives of cervical cancer among women may influence them to proactively seek cervical cancer prevention services or avoid it.

The study sought to understand explanatory models of cervical cancer among women attending the Cancer Diseases Hospital (CDH) in Lusaka for treatment. Using qualitative case study design, data were collected using in-depth personal interviews from 20 women aged between 25 to 59 years and were recorded and transcribed. Data were analysed using Thematic Analysis.

Women had different perceptions of disease aetiology with some believing it was witchcraft, while others believed it was because of eating foods sprayed with chemicals and from sexual intercourse with uncircumcised men. A few had no knowledge of the cause. As a result, women sought treatment from different avenues, ranging from prayer, traditional healers and witchdoctors, to conventional treatment. Some of the preventive measures mentioned were avoiding prostitution, good nutrition and male circumcision, while the majority reported not knowing how cervical cancer could be prevented. Of the 20 women interviewed, only two had been screened for cervical cancer. Some women revealed that they only heard of cervical cancer when they were referred to the CDH for management of their disease.

Women's lay perspectives of the disease differed significantly. How and whether they seek treatment and preventive measures is largely based on their construct of the disease. Those unaware of cervical cancer are more likely to believe they were bewitched and hence seek treatment from traditional healers and witch doctors. This study provided broad based insights on the constructions of cervical cancer among women with the disease. The study revealed that women do not have accurate information hence are less likely to seek screening and early detection of cervical cancer thereby leading to costly progression and management of the disease and poor treatment outcomes.

Keywords: Cervical cancer, qualitative case study, Lay perspectives, Thematic analysis, in-depth personal interviews, bewitched, witch doctor.

DEDICATION

This study is dedicated to my participants and patients at Cancer Disease Hospital who put up smiles on their faces despite the anxiety, the pain, the uncertainty, the fear and everything they were going through. They are strong women who deserve nothing but the best of health and health care.

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ACRONYMS

CCPPZ	Cervical Cancer Prevention Program in Zambia
CDC	Centers for Disease Control and Prevention
CIDRZ	Centre for Infectious Disease Research in Zambia
HIV	Human Immune deficiency Virus
IEC	Information, Education and Communication
MOH	Ministry of Health
MoCTA	Ministry of Chief and Traditional Affairs
NCCSP	National Cancer Control Strategic Plan
NGO	Non - Governmental Organization
NIH	National Institutes of Health
PEPFAR	Presidential Emergency Plan for AIDS Relief
SSA	Sub Sahara Africa
UTH	University Teaching Hospital
WHO	World Health Organization

CHAPTER ONE: INTRODUCTION

1.1 Background

Cervical cancer is a highly preventable disease (CDC.gov, 2012) and is the most common cancer among women in sub-Saharan Africa (Anorlu, 2008). Anorlu, (2008) writes that knowledge and awareness of this disease on the African continent are very poor and mortality still very high. An assessment of women's knowledge of cervical screening and cervical cancer was considered important as up to 92% of those dying from this form of cancer had never been tested (Neilson and Jones, 1998)

Cancers figure among the leading causes of morbidity and mortality worldwide, with approximately 14 million new cases and 8.2 million cancer related deaths in 2012. According to the World Health Organization (2015), around one third of cancer deaths are due to the five-leading behavioral and dietary risks: high body mass index, low fruit and vegetable intake, lack of physical activity, tobacco and alcohol use. Anorlu, (2008) contends that cervical cancer is the second most common cancer in women worldwide and the leading cause of cancer deaths in developing countries. Anorlu, (2008) further writes that while incidence and mortality rates of cervical cancer have fallen significantly in developed countries, 83% of all new cases that occur annually and 85% of all deaths from the disease occur in developing countries.

According to the Globcan (2012) globally, close to 500,000 women every year are diagnosed with cervical cancer and 250,000 women per year die with 80% of cancers and deaths occurring in women who live in developing nations.

Persistence of the human papilloma virus (HPV) is the major cause of cervical cancer and is transmitted sexually (in most cases) with 80% eliminated by immune system within ~ 18 months, in most cases (Mwanahamuntu et al; 2011). HPV is the main cause of cervical cancer and a common virus that is passed from one person to another during sex and at least half of sexually active people will have HPV at some point in their lives, but few women will get cervical cancer (CDC; 2012 and NIH; 1996). Cervical cancer can be prevented in two major ways; primary and secondary prevention. One of the primary prevention measures for cervical cancer involves the utilization of the HPV vaccine which is given to girls who have not been exposed to vaginal sex while secondary prevention involves early detection through cervical

cancer screening and treatment. According to the ZDHS 2013-2014, more than 90% of women aged 24 years have had sex before. Cervical HPV infection is a common sexually transmitted infection, with the highest prevalence seen in women under 25 years of age (Woodman, 2007). Woodman further contends that most women are infected shortly after beginning their first sexual relationship. The natural history of the disease takes about 10 to 20 years to develop into full blown invasive cervical cancer and is asymptomatic in its early stages (Schiffman, 2007). Cervical cancer is at its peak between 35-45 years of age (Mwanahamuntu ; 2011, CDC; 2012).

There are a number of factors that may lead to women having cervical cancer. These are not limited to, poor availability; poor accessibility; and poor quality of care provided, to women's lack of information and to cultural and behavioral barriers (Agurto, 2005).

Greater than 20% of the world's annual deaths from cervical cancer occur in sub-Saharan African countries, like Zambia, where cervical cancer is the most common malignancy and the leading cause of cancer-related deaths among women (Pfaendler, 2008). Similar sentiments were also echoed by Mwanahamuntu, (2009) who writes that, Zambia has one of the world's highest cervical cancer incidence rates (53.7/100 000 women/year) and also a national adult HIV seroprevalence rate of 16% (23% in Lusaka, the capital city (2014 adult HIV prevalence is at 13% according to the ZDHS 2014) (Zyaambo 2013) quoting Chokunonga, (1999), and Banda, (2001), writes that cervical cancer was the most common cancer in women in Zambia, with approximately 28% of all patients seen with Cancer at the Cancer Diseases Hospital in Lusaka experience this disease (Maree 2014). Studies conducted at the UTH revealed that cervical cancer was the most common cancer among women (Bowa, 2009).

Table 1: Key statistics on Zambia

Population		
Population at risk for cervical cancer	female population aged ≥ 15 yrs	3.90 million
Burden of cervical cancer		
Annual number of cervical cancer cases		2,330
Annual number of cervical cancer deaths		1,380
Crude incidence rates per 100,000 population		33.7
Crude mortality rate per 100,000 population		19.9
Age standardised mortality rate per 100,000 population		36.2
Burden of cervical HPV infection		
Prevalence (%) of HPV 16 and/or HPV 18 among women with:	Normal cytology	4.7 [†]
	Low-grade cervical lesions (LSIL/CIN-1)	26.5 [†]
	High-grade cervical lesions (HSIL/CIN-2/CIN-3/CIS)	43.9 [†]
	Cervical cancer	68.3 [†]
Factors contributing to cervical cancer		
Smoking prevalence (%), women		3.5
Total fertility rate (live births per women)		6.2
Oral contraceptive use (%)		
HIV prevalence (%), adults (15-49 years)		11.0

[†] The data is the sub-region Eastern Africa

(Bruni et al: 2014, iv)

Table 1: above shows the burden of cervical cancer in Zambia with high mortality rates (Crude and Age standardized mortality rates at 33.7 and 36.6 per 100,000 respectively). The figure

shows the cause of cervical cancer and highlights HPV as the major cause of cervical cancer and shows the factors that are attributed to contribute to causing cervical cancer.

The Cervical Cancer Prevention Program in Zambia (CCPPZ) a unit under the Center for Infectious Disease Research in Zambia (CIDRZ), a Non-Governmental Organisation, launched in 2006 and initially targeting the highest risk HIV-infected women, has cumulatively provided services to 100 000 women (regardless of HIV-status) over the past nine years (Mwanahamuntu et al; 2011). The program is being funded by the Presidents' Emergency Plan for AIDS Relief (PEPFAR) through Centers for Disease Control and prevention and has screened over 200 000 women with about 10% found with precervical cancer lesions and treated with Cryotherapy (Program reports; 2015). The program's motto is "every woman has a right to live a life free from cervical cancer".

Despite the disease being highly preventable through screening, early detection and early treatment, it has affected many households. No more than 5% of women in these settings are screened for cervical cancer even once in their lifetime and earlier attempts to establish population-based cervical cancer prevention programs using cytology screening in resource-limited settings have inevitably fallen short or failed (Mwanahamuntu et al, 2009). The low uptake of the cervical cancer screening services was due to [could have been explained by] the variety of prevalent 'folk' myths and misconceptions surrounding cervical cancer and its prevention methods (Chirwa, 2010). Due to the low uptake of the screening services within and outside Lusaka, the CCPPZ has come up with a number of innovative ideas like conducting Village-Based Screening to ensure that all eligible women in the far-flung villages are screened and those with positive results are treated for the disease. In Cameroun, despite the availability of the cost-effective cervical cancer screening strategies, screening remains low at 5%, (Ayissi 2012). Because of cervical cancer's devastating effects on the women, it is important that various communities are given accurate information on the effects of the disease and some of the treatment options should one be found with the disease. It is also important to have an understanding of what the women's constructions of cervical cancer are in the communities. These constructions have to a larger extent a bearing on the women's health seeking behavior as they will compel them to either seek cervical cancer prevention services or shun away from the service. Women's constructions of the disease have the potential to influence the women to seek

government instituted cervical cancer screening and treatment or the women can seek treatment from different sources depending on how they have interpreted the disease. Women would also be influenced by what is acceptable and the norm in their various communities on modes and sources of seeking health. They would also be influenced depending on whether they know or feel at risk of the disease or not. They will act based on the knowledge they have and the knowledge they have accepted to be beneficial to them and others in the community.

1.2 Statement of the problem

The Zambian National Cancer Control Strategic Plan (NCCSP, 2016-2021) indicates that there are 3.1 million women of reproductive age in Zambia, of which 2 million are eligible to be screened for cervical cancer. Of these women, only few have ever been screened. Mwanahamuntu, (2011) writes that only about 2.5% of women had screened for cervical cancer from 2006. Despite the high cervical cancer mortality rate in the SSA, women remain unscreened. This was also contended by Neilson and Jones, (1998) who write that, up to 92% of those dying from this form of cancer had never been tested or screened. In Zambia, there have been efforts by government and cooperating partners to reduce the burden of cervical cancer by providing free HPV Vaccine in selected districts with the proposals currently being developed to scale up the coverage of the vaccine country-wide (MoH, 2017 reports). According to MOH; 2016 reports, there are currently close to 50 free screening/awareness centres in about 40 out of the 104 districts of Zambia. These centres are few but they have, over time remained underutilized and not overwhelmed. Low uptake of services despite huge burden of the disease in Zambia remains a concern. The NCCSP (2016-2021) indicate that 70% of women with lower stages of cancer of the cervix with high cure rates have been for screening while 80% with high stages with low cure rates have never screened. Women with cervical cancer who present to the hospital late usually have symptoms of the disease for example vaginal bleeding, abnormal vaginal discharge, backache and lower abdominal pains etc. They may as well have different constructions or meanings of this disease and their health seeking behavior is usually dependent upon the meanings attached to the disease. These lay perspectives or constructions of disease by the women and the communities where they come from, may contribute to the low uptake of cervical cancer screening by women.

1.3 Significance of the study.

There is limited or no data on the lay perspectives or meanings of cervical cancer among women with cervical cancer disease. The main purpose of this study was not to attempt to generalize findings to the population but rather to find out what the lay perspectives of cervical cancer disease are and explore individual construction of cervical cancer and to facilitate the development of theory. The study sought to explain the low uptake of cervical cancer prevention services by developing ideas and theory from the individual constructions of the disease. The study can serve as a basis for future intervention and educational strategies that will ensure an increased uptake of the available cervical cancer prevention services. The study endeavored to collect the different meanings of cervical cancer from women with cervical cancer. This facilitated the development of ideas as to why some women may decide not to access the cervical cancer prevention services despite being available in some parts of the country and the knowledge of the devastating effects of the disease.

The findings of this study can also be used to enable planning of interventions that will take into consideration the women's understanding of the disease and some of the barriers and facilitators to accessing preventive services. A qualitative case study approach was used in this study, mainly to offer a framework for which the phenomenon will be understood with insights that will enable the generation of theory obtained. The findings of this study will also contribute to the generation of knowledge in the field of cervical cancer prevention.

Some studies have shown some of the experiences of women who have cervical cancer and a few showing the perceptions of women towards cervical cancer. Maree et al (2014) writes that, women with cervical cancer did not understand anything concerning the disease and they believed they were bewitched. It is also important to understand the social construction of cervical cancer disease from the women with cervical cancer and what their perceptions are with regards to what the disease is, its risk factors and the way the disease is being managed and what they believe should be the expected outcomes. This understanding enabled an in-depth understanding of the experiences that these women are faced with. It was important to have an understanding that will contribute to tailoring some of the educational messages to specifically target and convince women to seek cervical cancer prevention services from their own

understanding that could have given them a chance to change the course of life and avoid a life with cervical cancer.

1.4 Research Questions

What are the women's lay perspectives of cervical cancer disease?

Do these perspectives have an influence on their health seeking behavior towards cervical cancer prevention services?

1.5 Main Objective

To understand the lay perspectives to cervical cancer disease held by women with the disease at CDH.

1.6 Specific objectives

1. To determine women's perceptions of what cervical cancer is.
2. To explore the women's understanding of the causes of cervical cancer.
3. To assess women's perceptions on the most appropriate prevention and treatment methods for cervical cancer.
4. To understand if these perceptions attached to cervical cancer have an influence on women seeking cervical cancer prevention services.

Summary

This chapter gives a clear and distinct picture of the burden of cervical cancer from the global, regional and Zambian perspective. It explains the cause of cervical cancer and the natural history of the disease. It explains that cervical cancer is one of the highly preventable diseases. It is a cancer with the highest mortality rates in the SSA, yet the uptake for screening and early detection and a preventive measure remains low within the region. The chapter hence justifies why this study to understand whether the explanatory models of cervical cancer influence women's behavior towards seeking cervical cancer prevention services. The research questions as well as the objectives of the study to answer those questions have also been placed

CHAPTER TWO: LITERATURE REVIEW

This chapter presents a review of studies related to the subject of interest. Different search engines like Google, Google scholar, pub med and HINARI from which an overview of the literature review is given, were used.

2.1 Explanatory models

Explanatory models of disease are increasingly being used to allow for a better understanding of various diseases from a lay point of view. Explanatory models are a qualitative technique that utilize open-ended questions that help in the collection of perceptions and expression of feelings towards phenomena. Explanatory models are able to “integrate clinical, epidemiological and social science frameworks” and also aid in revealing how people make sense of their illness and provides a framework whereby social science researchers and healthcare providers engage with participants/patients in comprehensively understanding their lived illness experience (Weiss, et al 1992). Explanatory models are often used to explain how people view their illness in terms of how it happens, what causes it, how it affects them, and what will make them feel better (Kleinman, 1978). Bhui, and Bhugra, (2002) explain that this method is a tool that could be used alone in qualitative research, or with other techniques such as life histories, key-informant interviews, participant-observations, focus groups or pile sorting, among others. Kleinman’s models contain up to thirteen important questions which are as follows;

- 1) What do you call the problem you are experiencing?
- 2) What do other community members call this problem?
- 3) What do you think has caused the problem?
- 4) Why do you think it started when it did?
- 5) What do you think the sickness does? How does it work?
- 6) How severe is the sickness? Will it have a long or short course?
- 7) What kind of treatment do you think the people with this problem should receive?
- 8) Do you know where others with the same problem go for their treatment?

- 9) What are the most important results you hope to receive from this treatment?
- 10) What do you think is the appropriate prevention for this illness?
- 11) What are the chief problems the sickness has caused?
- 12) What do you fear most about the sickness?
- 13) Did you believe there was need to screen for cervical cancer then?

Explanatory models of illness encompass a person's ideas about the nature of their problem, its cause, severity, prognosis and treatment preferences (McCabe, 2004; Kleinman, 1980). Dissonance between patients' and professionals' explanatory models may affect help-seeking behavior (MacCarthy, 1988), treatment compliance (Foulks, 1986), satisfaction (Callan & Littlewood, 1998) and culturally sensitive clinical practice (Bhui & Bhugra, 2002). According to Cohen, (1994), the differences in explanatory models between client and practitioner have been suggested as reasons for non-compliance in several disorders. With cervical cancer being highly preventable, it should be understood that low uptake of screening and treatment could be explained by the women's understanding of what the disease could be, why they think they are affected and what they think the appropriate course of treatment for them should be.

A study that was conducted in West Africa to elicit information on explanatory models of causation of psychosis and questionnaire assessment of internalized stigma indicated that there is a greater tendency for persons with high levels of self-stigma than those with low levels to ascribe supernatural attribution to their experience of a severe mental health condition (Makanjuola, 2016). Another study conducted in South India to look at the association of explanatory models and distress among caregivers of people with acute psychotic illness revealed that majority of the caregivers simultaneously held multiple models of illness, which included medical and non-medical perspectives and concluded that explanatory models affect coping in caregivers of patients with acute psychotic presentation. Similarly, there is an indication that causal explanations are associated with various treatment outcomes, including attitudes towards treatment and satisfaction with therapeutic relationships as well as internalized stigma (Yalvaç 2016). A systematic review on the impact of causal explanations on outcome in people experiencing psychosis suggested that spiritual beliefs appeared to be adopted as a coping

mechanism and a way to reduce stigma but to the contrary, did not appear to be associated with treatment outcome (Carter, 2017).

Dein, (2004) contends that culture determines the different ways that patients understand cancer, the ways they explain it, and their attitudes towards it. He further writes that these factors affect the patient's emotional response to the disease and health behavior in terms of prevention and treatment. Szalacha et al (2016), agrees and also writes that; Practitioners should recognize that Latinas may differ in beliefs from other minorities, and that even within-group, there may be cultural differences that influence cancer screening behaviors in a study of knowledge and beliefs regarding breast and cervical cancer screening among Mexican-Heritage Latinas. Religious and cultural beliefs, such as the value placed on modesty and premarital virginity, contribute to reluctance to seek health care writes Matin and LeBaron, (2004). How treatment should have been executed and the prognosis of the disease is affected by the perceptions of those who are being treated. This study takes interest in these cultural perspectives and how they influence health seeking behavior among women. The interest is also to find out if this influence extends to cervical cancer prevention services.

2.2 Lay Health Beliefs

Individuals try to have an explanation for a particular disease for various reasons including as copying strategies and avoiding stigma. These beliefs have the potential for misinformation about a disease and individuals would seek treatment late and jeopardize treatment outcomes. In some instances, individuals may not seek appropriate treatment or may not seek treatment at all. They also want to have an explanation for the illness in line with their cultural norms and beliefs. Furnham (2017) writes that lay beliefs look at the typical types of explanations they favor for the cause of mental illnesses from biological and genetic to psychological and sociological. He further contends that, It also examines what people believe are the most efficacious ways of treating these problems from pharmaceutical cures to classic psychotherapy. Hardcastle (2017) contributed to this and wrote that; lay health beliefs, skepticism of eating guidelines, and a lack of motivation were barriers to change in a [qualitative study exploring health perceptions and factors influencing participation in health behaviors in colorectal cancer survivors](#).

“Although we hypothesized that women ever having an abnormal Pap test may have actively sought to learn more about cervical cancer and its prevention, findings suggest that this is not the

case. Informing women of an abnormal result could be coupled with a high-intensity counseling designed to improve attitudes and beliefs relative to women's role in protecting themselves from cervical cancer" Crosby (2016) wrote.

2.3 Women's lay perspective of cervical cancer

It is important to understand the lay perspectives of cervical cancer. This determines the efforts of cervical cancer screening, early diagnosis and treatment which are important to bring the prevalence of the disease down. With this understanding, interventions would be directed at addressing the misinformation as well as enhance the rightful and helpful information in addressing cervical cancer issues. An assessment of women's knowledge of cervical screening and cervical cancer was considered important as up to 92% of those dying from this form of cancer had never been tested (Neilson and Jones; 1998). Kim et al (2016), contends that, there was a lack of understanding and knowledge of cervical cancer; 47% reported that women will get cervical cancer because it runs in the family; 76% thought that smoking cannot cause cervical cancer; and 34% believed that cervical cancer is matter of Karma in a study on knowledge and cultural health beliefs of cervical cancer and attitudes and behaviors towards cervical cancer screening among Cambodian American women.

Explanatory models when applied to illness, the beliefs and values from a cultural model of disease influence perceptions about the meaning of an illness, the types of treatment that are useful, and the likely outcome of health behaviors related to the prevention and control of disease (Daher; 2012). In some cultures, Daher, (2012) continues that, cancer is seen as a punishment [for wrong doing].

Chirwa, et al (2010) showed in a study that women had varied responses to what they thought cervical cancer was. According to Chirwa, et al (2010), the top [...] myths and misconceptions were that; women believed that once one is found to have cervical cancer, it means they are a prostitute and/or that having sex with a married woman's husband can give one cervical cancer. Some women believed that cervical cancer was a satanic curse or one was bewitched (Chirwa, et al; 2010). The Eve Appeal cancer research indicates that one in five women associate gynecological cancers with sexual promiscuity while 40% feel that it comes with a greater stigma than other forms of cancer. According to the research, the stigma surrounding gynecological cancer means a quarter of women are avoiding going to their GP [General

Practitioner] because they're afraid of being judged on their sexual history (<http://www.marieclaire.co.uk/blogs/550342/cervical-cancer-myth>). Arbor, (2007) writes that among the 15 myths of cervical cancer is that women believed that once they are diagnosed with cervical cancer, they will die (www.cancer.med.umich.edu-15 *myths about cervical cancer*). Chirwa, et al (2010) indicated some myths and misconceptions that included the belief that, once someone has cervical cancer, then their womb is dirty and still others blamed it on family planning medicines. One other model is the belief that the disease is in the family and hence unavoidable. The insertion of traditional herbs inside the vagina was yet another belief among the women as to what could cause cervical cancer (Chirwa, 2010)

2.4 Why women have cervical cancer.

Because some women feel that there is blame on why they have the disease, it would be insightful to learn why they think it happened to them. Learning what could have caused them to have cervical cancer would help understand what their perceptions are on the treatment pathways and how they cooperate and adhere to the treatment schedules. Perceptions of why women have cancer have the potential to delay seeking appropriate treatment as they may seek other forms of treatment because of the belief of the disease etiology and outcomes. Symbolic meanings of the body need to be taken into account as this has to a greater extent an influence of perceptions of the disease. A study that was conducted in the USA revealed that symbolic meanings of the body are essentially related to a person's experiences and perceptions of health, illness, and health care ([Good, 1994](#); [Lupton, 2000](#)). The meaning of the body evolves from a person's daily lived experiences, constantly revised and transformed in social and cultural contexts, which constitutes a person's ideas and beliefs about health and illness (Good, 1994; Lupton, 2000). As the symbolic meanings of the body evolve, so do the perceptions and these perceptions have the potential to influence health seeking behavior.

2.5 Beliefs on causes of the cervical cancer

According to a study that was conducted looking at myths and misconceptions of cervical cancer, most of the responses to questions why women did not want to screen for cervical cancer correlated with the responses to what they thought was the cause of the disease. Some women indicated that they did not want to screen for cervical cancer because they believed that one would die once they know that they have the disease. (www.cancer.med.umich.edu-15 *myths about cervical cancer*) This shows how women respond to their own beliefs and their own health

seeking behaviors are affected by their beliefs. [Kleinman, \(1980\)](#) and [Kleinman & Seeman \(2000\)](#) contend that Individuals' beliefs about the cause and significance of a particular illness are interconnected with their healthcare-seeking behaviors. According to Kleinman's Illness Narratives Model, beliefs associated with an illness also tend to be linked with culturally influenced psychological and social characteristics (Lee et al 2007). Lee et al (2007) furthers writes that Healthcare providers should examine the women's culture-specific beliefs to target health education more effectively.

Summary

From the literature above, different explanatory models or constructions of disease by different individuals for different illnesses influenced their health seeking behavior. It can also be appreciated that the study will benefit from utilizing Arthur Kleinman's explanatory models of disease. This framework provides the background that supports our investigation and offers the reader a justification for the study of this particular research problem and to reduce biases that may sway interpretations (Abraham, 2008).

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Study Design

This was a qualitative study that focused on understanding individual constructions and lay perspectives of cervical cancer among women with the disease. A qualitative case study approach was used to explore these individual constructions of cervical cancer from the target participants. This study design was chosen as its relevance to the study that sought the participant own interpretations of the disease in their context and their in-depth understanding thereof. According to Cresswell, (Turner 2010), the case study method emphasizes on a detailed contextual analysis within a limited scope and the relationship therein. This study design was appropriate for the study as it enabled the researcher extract constructions about cervical cancer among women. The case study approach suited the research topic as it is dynamic and appropriate to understanding the constructions of illness of the research participants. It is a flexible approach as it allows for inclusion of the data that emerges at any point during the study. Case study approach uses open-ended questions and allows the researcher to enter into the world view of the participants and appreciate their environment, the interactions and interpretations of the phenomena of interest and enables the researcher to come up with rich descriptive meanings and develop theory which incorporates self, social settings and social object (Goulding, 1999)

3.2 Study site

This study was conducted in Lusaka at the Cancer Diseases Hospital which is one of the University Teaching Hospitals. Opened in 2007, the Cancer Diseases Hospital offers cancer patients, state-of-the-art radiation and chemotherapy services as well as palliative care for cancer patients within Zambia and the surrounding region (www.medicalzambia.com). The Hospital is currently the only cancer treatment center in the country. It is situated 4 km east of the central business district of Lusaka the capital city. The hospital was purposively selected as a study site because it is the only referral hospital and cancer disease treatment center in the country for all suspected and confirmed cases of cervical cancer. The hospital attends to about 2000 cervical cancer patients per year (www.medicalzambia.com).

Figure 1. Picture of the study site



3.3 Study population

Women aged between 25 to 59 years old with diagnosed cervical cancer disease were included in the study. Zambia's National Cancer Control Plan 2016-2021 guides that women who have been exposed to vaginal sex between 25 to 59 years and women that are HIV infected if sexually exposed, regardless of their age shall be actively screened for cervical cancer in all facilities that provide the service.

This age group (25 to 59 years) was strategically selected because it included the age range 35 to 45 years where cervical cancer is at its peak considering the age of first sexual debut and the natural history of the disease. Women in this age group can legally make informed consent to participate in the research study. Cervical cancer patients that were critically ill were excluded from study participation. Cervical cancer patients that were not able to provide informed consent were also excluded from the study. Women were purposively selected in the cervical cancer ward. This selection criteria used made it possible for patients with different ages, educational background and marital status be included.

3.4 Sample size and Sampling procedures

Purposive sampling was used for the sample of 20 participants. Purposive sampling is a form of non-probability sampling in which decisions concerning individuals to be included in the sample are taken by the researcher based upon a variety of criteria which may include specialist knowledge of the research issue or capacity and willingness to participate in the research (Boyce,

2006). The number of participants chosen was reached at after being guided by literature that involved qualitative studies and more specifically, case study designs. The women at CDH, where patients with cervical cancer are being attended to and lodging were initially categorized using the familiar categories or variables such as marital status, education attainment and age of the women. Women in the ward were highly mobile going to and from their scheduled treatment and doctor appointments. The women would return from their treatment episode feeling and looking weak. This made interviewing women a challenge; hence convenient sampling was also employed in that women who were found in the ward and available for the interview as long as they met the eligibility criteria and were able to give informed consent were interviewed.

3.5 Inclusion and exclusion criteria

Women that were included in the study were between 25 to 59 years old and were able to read or comprehend and sign or thumb print on the informed consent for study participation. The women included were those who were given a confirmed diagnosis of cervical cancer and had received their result.

Women who were not able to comprehend the informed consent and the objectives of the study were not included for participation. Even those who were too sick to participate or too weak after a session of treatment were not included for participation.

3.6 Data collection

This study performed in-depth personal interviews using an interview guide for data collection from the eligible participants. In-depth Interviews are among the common methods of data collection in qualitative research where in-depth data about the participants are collected. Each interview was guided using open-ended questions adopted from the Kleinman's explanatory model (1978) refer to appendix 2. The interviews took an average of 30 minutes. These were conducted privately on the participant's bedside away from the hearing of other women or staff on the ward. The interviews were voice recorded and data was transcribed word for word onto scripts. All interviews were conducted by the Principle Investigator. The following are the questions that were asked by the investigator;

14) What do you call the problem you are experiencing?

15) What do other community members call this problem?

- 16) What do you think has caused the problem?
- 17) Why do you think it started when it did?
- 18) What do you think the sickness does? How does it work?
- 19) How severe is the sickness? Will it have a long or short course?
- 20) What kind of treatment do you think the people with this problem should receive?
- 21) Do you know where others with the same problem go for their treatment?
- 22) What are the most important results you hope she receives from this treatment?
- 23) What do you think is the appropriate prevention for this illness?
- 24) What are the chief problems the sickness has caused?
- 25) What do you fear most about the sickness?
- 26) Did you believe there was need to screen for cervical cancer then?

Memoing was also conducted to include any observations and non-verbal expressions exhibited by the study participants. These ensured participants' different expressions and behaviors were recorded and included in the reporting.

3.7 Data Management and Analysis

After all data were collected, they were transcribed verbatim. Data was then manually organized in readiness for analysis. At this stage, all responses to specific question by each participant were displayed in a single spreadsheet to allow for easier picking out of concepts and themes. A theme is a cluster of linked categories conveying similar meanings and usually emerges through the inductive analytic process which characterizes the qualitative paradigm (Martyn, 2010). Thematic data analysis was used to analyze the data. Thematic data analysis is a qualitative analytic method for:

“Identifying, analyzing and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic” (Braun and Clarke, 2006).

The six steps of thematic data analysis guided by Braun and Clarke (2006) was employed. Firstly, there was familiarization to the data where there was a lot reading and re-reading of the transcripts and listening to the recordings. Initial ideas were recorded and comprehended as an initial stage for the analysis. Transcripts were examined line-by-line to identify words, thoughts, actions, feelings that were then coded.

Secondly, initial codes as a preliminary step were identified where interesting and meaningful data was identified. This aided in generating and organizing 'like' data with similar codes that were systematically done across the entire data set, either by adding to the earlier developed codes or generating new codes to ensure all meanings were captured. These provided an indication of the context of the conversation.

This was followed by the third step which was a process of collating the codes where relevant data extracts were sorted according to overarching themes. This process led to the fourth stage of reviewing the identified themes and the merging of coherent themes, refining and discarding some of the created themes was done.

Themes and subthemes were then defined and named as step five with the final step allowing the investigator to come up with interpretive and compelling extracts that were related to the themes and subthemes, research question and literature. Theoretical constructs were reviewed to capture relationships and processes that were identified in the earlier stages of data analysis. Comparative analysis was employed to compare the emerging theory to the existing theories.

3.8 Ethical Considerations

This study involved understanding women's lay perspectives of cervical cancer. Firstly, cervical cancer carries some stigma because of the way it is transmitted (mainly sexually). It is for this reason that it remained a sensitive issue to discuss. Talking to the women and collecting data from them can cause some anxiety and self-stigma.

3.8.1 Approval

The study obtained protocol and informed consent approval from the University of Zambia Biomedical Research Ethics Committee (UNZABREC). Additional approval was obtained from the Cancer Diseases Hospital research approving committee. Permission and verbal approval was given by the Chief Nursing officer at CDH and the Nurse in-Charge of the cervical cancer wards.

The investigator obtained informed consent from the potential participants after reading the information sheet and ensuring that the participant had comprehended and signed the informed consent before proceeding to audio-record and collect data from the participant.

3.8.2 Respect for Participants and Confidentiality

Anonymity was pursued by the use of identification numbers and not actual participants' names or other identifiers. Data collected from the participants remained confidential throughout the process of data collection, analysis and reporting. It was not availed to any unauthorized individuals or institutions.

Participants were treated as autonomous individuals who had the right to make decisions of their health including to or not to participate in this or other studies. All research materials that contain participants' responses will be destroyed after 1 year of study completion per this protocol.

3.8.3 Beneficence

The study aimed to do no harm (Non-Maleficence) but to do good at all times. Minimal anxiety and restlessness anticipated during interviews with women who already have cervical cancer was noted. The investigator ensured the comfort of the participant and built a rapport and reassured the client of confidentiality before proceeding with the interviews to gain trust and confidence from the women. Women were also advised to be in the most comfortable position during the interviews as most of them had health ailments that prevented them to seat upright.

3.8.4 Justice

All the women were informed on how they were selected to enroll in the study. The selection criteria were justly done to the greater good of all women in Zambia. Women were informed of their right to withdraw at any point during the study and that their health care access will not be compromised by their refusal to continue participating in the study.

Summary

This chapter showed the methodology that was adopted for this study It also gave an explanation why this was the appropriate and best fit method for the phenomenon of interest. This chapter gave a clear and concise picture of the process that was employed to answer the research questions posed to help achieve the objectives.

CHAPTER FOUR: STUDY FINDINGS

This chapter presents qualitative findings of the study. A total of 20 Participants were interviewed and below is the brief description and demographic characteristics of the participants followed by the presentation of major and subthemes that emerged from the study. Verbatim quotations have been used to illustrate sub-themes. To ensure anonymity and confidentiality of participants, relevant demographics and participant characteristics have been used.

4.1 Demographic Characteristics of participants

The participants that were interviewed were compared in terms of the age, marital status, and educational attainment. Participants were between the ages of 25 to 59. The study showed that the majority of the women who were interviewed were between the age ranges 35-54 years old still with the majority having only attained up to grade 7 in their education. About half of the women interviewed were married.

Below is the table showing demographic characteristics of the participants that were interviewed at CDH;

Table 2: Demographical Characteristics

Characteristics	Number of participants
Age Range	
25-34	2
35-44	8
45-54	10
55-59	1
Marital status	

Married	11
Not married	9
Education Attainment	
Grade 0-7	10
Grade 8-9	4
Grade 10-12	4
College or University	2

The table below shows the major themes and sub-themes that emerged from the data. These themes were the basis for presentation of the data.

Table 3. Major and Sub-themes

Major themes	Sub- themes
<u>Perceptions on what cervical cancer is</u>	<ul style="list-style-type: none"> • Witchcraft • Menopause • just an illness • an incurable disease that eats up the body • just a smelly watery vaginal illness
Understanding the cause of the disease	<ul style="list-style-type: none"> • Bewitched by husband's girlfriend • Just an illness eating chemicals in food

- uncircumcised men
- no knowledge on cause

Perceptions on Prevention

- Did not know how to prevent the disease
- Avoiding prostitution
- Good nutrition
- Male circumcision

Perceptions on treatment

- Treatment from witchdoctors
- treatment from the hospital
- removal of the uterus

Challenges due to the disease

- Financial challenges
 - fear of death
 - body weakness
 - stigma
 - fear of not knowing the treatment outcome
-

4.2 Perceptions about cervical cancer

Women were asked what they thought cervical cancer was. They had a wide range of responses and constructions of cervical cancer. These ranged from witchcraft, menopause while others had

no knowledge of what the disease was and said it was just another of the illnesses with some believing that it was a disease that eats up the body.

4.2.1 Witchcraft

A good number (8) of the women interviewed felt they were being bewitched by either the husband's girlfriend or their husband's other wife/wives. One woman believed that the disease she was experiencing was as a result of the husband's relatives even when the husband's relatives thought she was the cause of the problem. The relatives felt that the participant had brought the disease (cervical cancer) upon their brother and she was being asked to leave the marriage because of this. One of the women, 32-year-old who had her husband leave the matrimonial home for another woman, believed that the disease was caused by her husband's girlfriend. She believed so when she developed the symptoms of the disease soon after a confrontation with the husband's new girlfriend.

She said;

“...before I came here at the hospital, I thought I was being bewitched by my husband's girlfriend. Why I thought so was because, just before I had this problem, my husband married a woman from Malawi. So, that woman started saying and warning me that I will never see my husband again as she was a Chewa from Malawi. Before long, I started having a watery vaginal discharge and that was when I thought I had been bewitched...”

4.2.2 Menopause

Two participants mentioned that when they developed the symptoms, they believed it was menopause. This was because they had advanced in age and had reached age of menopause which seemed a normal occurrence for them. An elderly woman who had reached menopause later developed vaginal bleeding and thought intermittent vaginal bleeding was a normal occurrence. This understanding made some women not to seek any medical advice soon after seeing this symptom. This is evidenced by a 48 year old unmarried woman as she contended that, *...before I was told it was cervical cancer, I thought it was just menopause, I started by skipping my monthly periods, I could go 2 months, then I skip, 3 months, no periods but when it got so heavy, I got suspicious....*

4.2.3 Just a Disease

Some women mentioned that cervical cancer was just an illness like any other illness. One married, 36-year-old woman mentioned that the disease is just another disease that eats up the body. “It is one of the diseases that one can come across in life”. There was a mention that this disease is an incurable disease that eats up the body while another woman mentioned that she did not know what it was but just a disease with a smelly vaginal discharge. A 44-year-old widowed woman believed it was just a Bemba disease as she said; *...it is just a Bemba disease called akasele...*

4.2.4 Lack of Knowledge

Many participants did not know the signs and symptoms of cervical cancer and attributed what they were experiencing to other factors, disease or cause. A few yet had no idea what cervical cancer was and did not associate their symptoms to it or to any disease.

Another participant said she did not know what the disease was and when she asked some community members, some told her that it was just a disease just like any other but discouraged her from seeking medical attention because they believed it was in the clinics where they would get diseases from. *... they said that is your fault, in these clinics where you go. You will just get sick and they will give you some more diseases if you continue going to these clinics...* said a 59-year-old woman.

Yet another participant contended that she thought it was just some disease that has no cure and you just wait for time to die. This was at the time before she came into contact with information about cervical cancer and what it is. She has now departed from that information after she was sensitized on what cervical cancer is. *... I just thought it was some disease which was so difficult to treat and it will just lead you to death and you just wait there hopelessly and just die one day...*

4.3 Understanding the Cause of the disease

We asked the participants’ understanding of what they believed was the cause of the disease they were experiencing. Again, there were many different responses to what they believed caused the disease. The women believed the disease came up because of supernatural causes, uncircumcised men, and chemical in the grown food that people eat while there were still others that lacked knowledge on the cause of the disease they had.

4.3.1 Supernatural Cause

When asked what women believed could have caused the disease, there were some that perceived it to have been supernaturally caused with some saying it was because God allowed it while some and in the majority had an initial belief that the disease was caused by witchcraft. A number of them mentioned in various languages what they thought was happening to them, which translates to prolonged menstrual period or vaginal bleeding where a girlfriend or another wife of the husband would use witchcraft to cause the bleeding to prevent them from having sexual relations with the shared husband. This was mainly in polygamous marriages or where the husband had a girlfriend. Most of the women mentioned that this was mainly before they were sensitized and educated about the disease, its aetiology, prevention and treatment. This was what they believed or told by the relatives or other community members they had consulted or told of their condition. One woman 35 year old and married said;

“...for me, I was convinced I was being bewitched. I even went to the witchdoctor for treatment with some traditional medicine and I told him I was being bewitched by my husband’s girlfriends, he gave me the medicine and I felt better at the time before it [the disease] came back...”

Another participant mentioned that she was surprised she had the disease as she believed was caused by stepping bare feet on the urine of a person who had the disease, or wearing their clothes or seating where they sat which she never did. According to an unmarried 52 year old woman;

“...this disease comes as a result of stepping bare feet on the urine of the one who had the disease before, more especially if you step in the bathing room bare feet, you can get the disease. Also, if you sat where the person with the disease sat or wear their clothes, you can get the disease...”

4.3.2 Uncircumcised men

Uncircumcised men as the cause of the disease was mentioned by 2 women. One woman aged 44 years, mentioned that she heard this when there was a sensitization talk during the former first lady’s visit to the district, where they were providing cervical cancer screening outreach even though she did not go as she felt lazy.

Not categorically stating that the disease comes from uncircumcised men, one participant, 52 years old stated that; *...the disease comes also from men who picked the disease from other women, they can transfer it to you during sexual contact...*

4.3.3 Chemical in food

When asked what women thought was the cause of the disease they were going through, one woman indicated that the disease is brought about because of eating a lot of fast-growing chickens which are given a lot of drugs to grow fast and the chemicals that are sprayed in vegetables. She also mentioned the chemicals that are in the soaps that are used for bathing that would bring cancer. The woman 50 years old mentioned that;

“...the rape that we eat, tomatoes and sweet potatoes that people grow with chemicals can cause cancer together with the chickens that people grow and they put a lot of chemicals and drugs and the chickens are ready within 2 weeks causes cancer...”

4.3.4 Lack of knowledge about the cause of cervical cancer

Some women when asked what they believed was the cause of the disease said they had no knowledge of what the cause of the disease was. One woman mentioned that she had no idea what the disease was but was thinking it was due to her low CD4 count as she was HIV infected. Another woman mentioned that she did not know and did not think of anything, *....i did not know what it was as I was elderly and stopped having children but I kept wondering why I was bleeding [vaginal bleeding]...*

4.4 Perceptions on Prevention

Women were asked what they thought was the appropriate prevention according to their understanding. There was a wide range of understanding or perceptions on cervical cancer prevention. Some women mentioned that they did not know what the appropriate prevention was as some had not heard about the disease itself while others heard about it but were not aware of the prevention. According to the findings, some women did not know how to prevent the disease, others mentioned avoiding prostitution, good nutrition and male circumcision

4.4.1 Avoiding prostitution

There were women who mentioned that avoiding prostitution is an appropriate preventive measure. This was when women were asked what they perceived to be the appropriate prevention for the disease. They believed that being promiscuous was the cause of the disease. A

46 year old woman mentioned that she also thought that the disease was brought about because of being promiscuous but when she came into hospital and found that there were many patients of different ages, she wondered whether that was the actual cause as there were young women, the aged and all other categories. She contended that;

“... when i came here at the hospital, i was surprised to see so many women in the ward with the same problem, there are old women, young women, women of all kinds so does it mean that even the old women, it is about being promiscuous...”

However, another woman, 41 year old and married with cervical cancer Stage 2b, to the contrary contended that, “... even when people say that this disease comes as a result of promiscuity, how come here [at the CDH] are different types of women, rich, poor, young and even very old women, would we say that the old women are promiscuous too?...”

4.4.2 Good nutrition

Some women believed that a good nutrition would prevent cervical cancer. They also believed that avoiding certain types of foods would help prevent the disease. When they were asked which foods in particular, one woman said that avoiding foods like vegetables, sweet potatoes that are sprayed with chemicals and chickens that grow fast because of chemicals. Another woman said one should just avoid foods that are not allowed and follow what the doctors say as there are many foods that are forbidden, the doctors know which foods these are.

A 35-year-old woman was asked what she thought was the best prevention for cervical cancer. After a long silence, she said ... *mmmhhh, from my experience, I think the best prevention is having good nutrition...*

4.4.3 Male circumcision

A few women mentioned that men needed to be circumcised to prevent cervical cancer. Like one woman attested to that fact and said after being asked what she thought was the appropriate prevention for cervical cancer;

“...male circumcision is number on the list [of preventive measures] because we understand that it is the men who are depositing these viruses from one woman to the other ...to reduce the already predisposed bodies from erupting...mmhh!...”

In agreement, another woman aged 53 years mentioned that men who are not circumcised can bring cervical cancer according to how she has been educated.

4.4.4 Did not know how to prevent the disease

When women were asked what they thought were the appropriate preventive measures, the majority of them displayed ignorance on what they needed to do to prevent the disease. The women interviewed merely said they did not know. Despite some women having been in the hospital for a few weeks prior to the interview, learning quite a bit about the disease, they did not remember learning what the prevention was. A 52-year-old woman stated that "...us, we live in the village in [...] and we can't know how to prevent the disease..."

4.5 Perceptions on treatment

Participants had different perceptions and expressions on treatment. Some of the participants expressed shock with the kind of treatment they found when they were referred to the hospital. These perceptions included; treatment from witchdoctors, treatment from the hospital, removal of the uterus and cervix.

4.5.1 Treatment from witchdoctors

Many participants believed initially that they were bewitched when they started having symptoms of the disease. They also believed that the only help they could get in form of treatment would be from the witch doctors or traditional healers. Six women mentioned that they went to the traditional healers but could not get help enough and hence ended up at the hospital with advanced disease. One participant, a 42-year-old from within Lusaka mentioned that she underwent a series of prayers as she thought that she was being bewitched by the sister to her husband. According to a 35-year-old woman, she stated that;

"...for me, I was convinced I was being bewitched. I even went to the witchdoctor to find me traditional medicine and I told him I was being bewitched by my husband's girlfriends [...] So, he gave me medicines for inserting [inside the vagina], for bathing, for drinking, for applying..."

4.5.2 Treatment from the hospital

Four women mentioned that now they think it is better for women with this problem to go to the hospital for treatment unlike what they believed was the appropriate treatment before they were exposed to information.

A few of them mentioned that the only kind of treatment that would help would be to go to the hospital. They believed that the hospitals should be equipped to help them with the treatment of the disease. They mentioned that they had never been to any other treatment centre but came straight to the hospital immediately they saw the symptoms. One woman, 44 year old, educated to tertiary, conveyed displeasure of the whole system and mentioned that the disease was serious and needed special attention by government. She said there was no way the country can depend so much on one hospital to cater for the entire country when the disease had affected many people.

“...we are told that this disease affects many and for sure it is a bad disease, so why are we told to come to Lusaka to the cancer diseases hospital and that it is the only hospital in the country that caters for all people in the country with cancer? Government should help the situation ...”

4.5.3 Removal of the uterus

Most of the participants' initial thoughts were that they would just have their uteruses removed and that would be the end of the treatment. One woman commented that because she was in so much pain, she went to the hospital and asked them to remove the whole cervix and the uterus.

“... mamamama! When I felt too much pain in my abdomen and back, I went to Choma hospital and told them to just remove the whole cervix and the uterus, I told them I had no use for them anymore, especially if it doesn't kill...” according to 52-year-old woman.

4.6 Anticipated/desired results from this treatment.

Most participants desired to get better after going through a long and painful treatment procedure. One young participant who was 28 years old mentioned that all she wanted to hear from the doctors was that the treatment was successful and that she is free of cervical cancer. She mentioned that she refuses to ever have cervical cancer in her life as it was a very bad disease. ... *I am healed and I will never get sick of cervical cancer, I refuse to get this sickness ever again...*

4.7 Alternative sources of treatment

Some participants mentioned that they had heard that some people go to witchdoctors and others to the hospital. Within the same community where participants come from were different views of the possible alternative treatment sources. One participant mentioned that she got confused as her relatives took her for prayers while she wanted to go to the hospital for treatment. She

mentioned that it gets confusing because firstly you don't know what the disease is and hence you cannot know what the treatment would be, so it was trying and error most of the time. "... There was a lot of confusion, we thought of a lot of different things, they took me for prayers, I went to the clinic myself until they referred me to the hospital..." contends a 41-year-old woman

4.8 Influence on the onset of the disease

When participants were asked what they thought could have influenced the onset of the disease at the point it started, some of them said they had no idea why it started at that particular time. Some thought it started because they stopped having children. One participant 48-year-old, mentioned that she thought the disease came about as a result of being bewitched after she had an altercation with the neighbour. "...I thought the neighbour had done something or made me step on something [...] that was when it all started..."

4.9 How the disease works or what it does

The majority of participants did not understand the basic detail about the disease. Some of them learnt about it when they were in hospital after the doctors and other health workers explained to them. Most of the participants mentioned that they still have no idea how this disease works. A 48-year-old participant said; *...I was told it eats up the uterus but am not sure how it does that. I was just told...*

Another one also mentioned that the disease is a long one for others while shorter for others but it destroys the body and is incurable.

4.10 Challenges due to the disease

Participants were asked what challenges they had faced or were still facing as a result of cervical cancer they had.

4.10.1 Financial Challenges

There were varied responses among participants. Some of the frequently talked about challenges were the loss of business, leading to the loss of finances or an income as some of them were breadwinners. Some expressed sadness that they could no longer adequately support their food supply and other essentials in the hospital as well as at home because their business was the only source of income. Two participants mentioned that the children had stopped going to school because they could no longer finance their school fees and other requirements. There was loss of a marriage by one of the participants. According to the 35 year old participant, *...there was no*

way a man can stay for a long time without having sex due to having prolonged vaginal bleeding... she continued that;

“...this problem does not give you peace, the bleeding gets to be too much and backache. The man ran away because there is nothing he would be staying for at home as you know men can't hold their hearts. They can't live without sex like us women do. They can't live for a month or 2 without sleeping with a woman...”

4.10.2 Fear of death

The fear of death was real for others who mentioned that they worried about who would take care of their children or grandchildren. Another participant mentioned how she was psychologically discouraged and afraid when she saw how fast some of the women in the hospital ward deteriorated after undergoing treatment , . She mentioned that her friends came to visit her at the hospital and they said they knew some people who use traditional medicine who could help her and she was not sure whether to try that or not.

“...from the time I came to the hospital...some women who came to visit me have said they will never go for screening because some white man is coming back with the virus to insert into these women so that they get what they want...” (44 year old woman)

4.10.3 Body weakness

Another challenge that was frequently heard was that the body had become weak due to the disease hence women were not able to be as productive as they were before. This, to them meant they could not farm the land and hence not enough food for the family and the little money they had, had to be used for hospital bills and transport. A 52-year-old widowed participant from the distant part of Zambia confirmed this as she said

“...I went to church to ask for some money to go to the hospital as I had exhausted what I had. The women's group call bana KBB are the ones that helped me with the money after the pastor approved...”

4.10.4 Fear of not knowing the treatment outcomes

Some women mentioned other fears like not knowing whether they will be healed or not and others that they are the ones who took care of the children hence are not sure how the children are surviving without them more especially if they died.

4.10.5 Stigma

With others mentioning how they suffered stigma and discrimination from relatives and friends because of the disease, one woman aged 42 said amid her tears that;

“... the way my sister in-law (husband’s elder sister) treated me, I will never forget and I will never forgive her. She used to scold me that I have infected their brother with this disease and that I should pack my bags and leave their brother...”

4.11 Perceived need for screening prior to the onset of the disease

Participants were asked if they thought screening for cervical cancer was important at the time and if they had screened before. All of the participants except two confessed to have never screened before as some said they did not see the need while others mentioned that they had heard that they screen but they did not have no screening clinic nearby. ... *no, it wasn’t even in my mind despite having heard that they were checking at a nearby hospital until I had the disease...*

According to the 39-year-old business woman, she said;

“... I used to hear people going around in the compound, telling people to go for screening but I thought they were just making noise and that the disease is meant for other people and not me...”

A few participants said they had never even heard of the disease until they were told so at the hospital. One woman mentioned that she didn’t even know the disease existed and that there was no education of the disease in most parts of the country.

Summary

This chapter interestingly brought out the findings from the research participants and also showed evidence of how they expressed themselves through quotes at different levels. Respondents were found in the cervical cancer ward at CDH but they come from different parts of the country as CDH is the only cancer treatment centre in the country. Some responses were similar while others were very different depending on where they come from which could indicate different cultural beliefs for different parts of the country.

CHAPTER FIVE: DISCUSSION OF THE FINDINGS

The study aimed at understanding the explanatory models of cervical cancer among patients at CDH. This chapter therefore, will provide for the discussion of the findings that emerged from the study as described in chapter four. This chapter will also attempt to interpret and describe the significance of these findings comparing with what is already known.

The study revealed that the majority (18) of women interviewed (found in the cervical cancer hospital ward) were between 35-54 years old. Invasive cancer arises over many years, even decades, in women with the persistent infection of HPV, with a peak or plateau in risk at about 35–55 years of age (Schiffman, et al 2007). This finding is consistent with Mwanahamuntu, 2011 and CDC; 2012) who reported that cervical cancer is at its peak between the ages of 35-59 years old. The National Cancer Control Strategic Plan (2016-2012) requires women between the ages 25-59 years to get screened for cervical cancer following the natural history of cervical cancer with signs and symptoms starting to show around that age range.

The study also revealed that half of those interviewed had only attained primary level education (between grade 0-7) while slightly above half (11) reported to have been currently married. Additionally, cervical cancer risk increased with increasing age, age at menarche, and age at marriage, while the risk decreased with increasing level of education and in those with some form of employment compared to housewives (Muwonge, 2016)

5.1 Explanatory models and cervical cancer

Explanatory models of illness encompass a person's ideas about the nature of their problem, its cause, severity, prognosis and treatment preferences (Kleinman, 1980). This study revealed that the participants had multiple explanatory models of cervical cancer. These perceptions are important as patients are being managed because they influence treatment compliance and outcomes. Gidron (2013) writes that the notion [Explanatory Models of illness] has been applied to prediction of patient coping and adherence with treatments and to prediction of disease outcomes. Buus et al (2012) also agrees and contends that, patients' personal beliefs about depression and antidepressants are regarded as central influences on adherence.

A strong interest in the understanding, exploring, and extracting explanatory models of psychosis has recently arisen. Explanatory models (EMs) offer justifications and propose explanations when coping with and treating illnesses. Bhikha et al (2015) states that the results suggest that patients hold multi-explanatory models in order to make sense of their illness and these stem from deep rooted traditional beliefs. This highlights the importance of educational intervention, culturally adapted psychological interventions and possibly working together with traditional healers in the UK to provide a positive support system.

This study suggested that most participants believed the disease was as a result of supernatural influence. This was mainly attributed to because of not having appropriate knowledge and education of what the disease was. Women had to explain what the disease was at least in some way and according to their interpretation and understanding which could have been influenced by a number of factors ranging from their cultural beliefs, their level of education, influence of the understanding of similar symptoms within their communities etc. A systematic review that was conducted by Bhikha, (2012) revealed that the majority of studies reported predominantly supernatural and psychosocial Explanatory Models of Psychosis-EMOP. He further reported that holding supernatural and psychosocial explanatory models affected help-seeking behavior, treatment modalities used and DUP (Duration of Untreated Psychosis).

According to the biomedical explanation, cervical cancer occurs when abnormal cells develop and spread in the cervix, the lower part of the uterus. Cervical cancer is also the uncontrolled growth of the cells of the cervix.

5.2 Explanatory models and causes of cervical cancer.

This study significantly revealed that most of the participants sighted supernatural cause of the illness more frequently than they sighted biological or other causes. Most participants believed that their illness was caused by witchcraft while others had other views concerning the cause. These were the catching beliefs of some participants more especially before their beliefs were influences otherwise by the health workers that they came in contact with when they sought treatment at the hospital. According to Walboomers, (1999), the international Biological Study on cervical cancer (IBSCC) study of invasive cervical cancers collected from 22 countries reported a worldwide HPV prevalence of 93% base on the MY09/11 polymerase chain reaction (PCR) assay. Walboomers further contends that failure to detect HPV DNA in the 7 percent of

these cervical carcinomas may have been due to either the absence of HPV DNA in the carcinoma cells or a false-positive HPV result. Schiffman, (2007) write that, Persistent infection with one of about 15 genotypes of carcinogenic human papillomavirus (HPV) causes almost all cases. Saslow, (2012) also writes that epidemiologic case series have shown that nearly 100% of cervical cancer cases test positive for HPV. Saslow., (2012) further writes that HPV type 16 (HPV16) is the most carcinogenic HPV genotype and accounts for approximately 55% to 60% of all cervical cancers. There is enough evidence to suggest that HPV subtypes cause cervical cancer unlike the belief by most women that cervical cancer is caused by witchcraft-supernatural cause. This contrast of the cause of cervical cancer by science and the participant is significant as it influences treatment satisfaction and to a larger extent, compliance.

Apart from the understanding that cancer was caused by supernatural causes, other women had limited knowledge on what cervical cancer was and its causes. Some women had not heard about the disease and or its symptoms hence expressed surprise when they developed the symptoms. This revealed lack of or limited sensitization and education among the players in cervical cancer prevention programs. The coverage of the cervical cancer awareness campaigns is limited in Zambia and reaching the women in far flung areas is a challenge. Anorlu, (2008), writes that Knowledge and awareness of the disease [cervical cancer] on the continent [African] are very poor and mortality still high. He further contents that, facilities for the prevention and treatment of cervical cancer are still very inadequate in many countries in the region... and governments in SSA must recognize cervical cancer as a major public health concern and allocate appropriate resources for its prevention and treatment, and for research. Indeed, cervical cancer in this region must be accorded the same priority as HIV, malaria, tuberculosis and childhood immunizations. A study that was conducted in South Africa, seeking to establish the level of knowledge about cervical cancer, risk factors and prevention, done by Hoque, (2010), revealed that only 33% of the University of Mangosuthu were aware of cervical cancer. Contrary to this finding, a study that was conducted in Ibadan where 71% of the undergraduate students were aware of cervical cancer (Ayinde, 2004) while a similar study conducted in America revealed that 70% of adults 18 years and older have never heard of HPV the causative agent for cervical cancer (Kaiser Family Foundation, 2000). The role of media and other contextual forms of information dissemination should be employed to ensure messages about cervical cancer, risk factors and prevention are disseminated to the underserved women in various parts of Zambia.

The results of a study that looked at the beliefs about the risk factors for cervical cancer in a British population suggest that culturally related beliefs about the etiology of cervical cancer play a role in the decision to obtain Pap smears for Latina immigrants (Waller, McCaffery and Wardle, 2004). This was similar to the findings of this study where the beliefs of the women that were interviewed initially influenced their behavior towards the course of the disease, when and where to seek treatment and why they sought that choice of treatment.

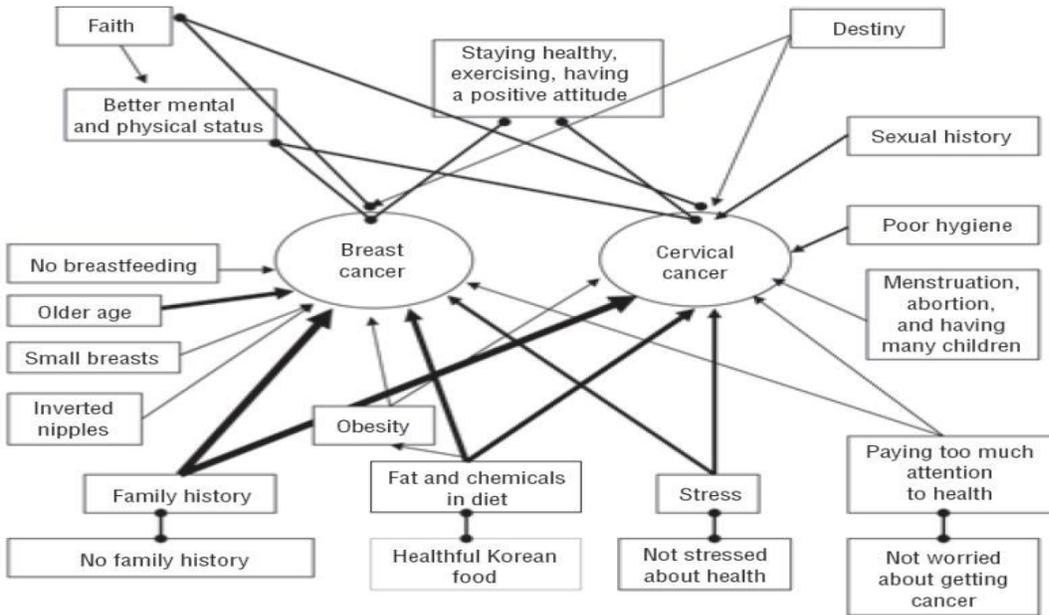


Figure 2 Conceptual diagram on beliefs of the cause of cervical cancer

The diagram below summarizes the beliefs of the causes of cervical [and breast cancer] among a target population in a study conducted in the USA on Korean American Women’s Beliefs About Breast and Cervical Cancer and Associated Symbolic Meanings.

The diagram showed different and varied believed causes of cervical and breast cancer and has shown, in many ways consistency and in agreement with the findings of this study. This study found that women believed that cervical cancer was caused by chemicals in food that individuals eat, sexual history particularly promiscuity and family history which this study also found.

5.3 Explanatory models and perceptions on prevention

The majority of the participants did not know what the prevention for cervical cancer was as revealed by this study. This still pointed to lack of or inadequate awareness and educational campaigns. According to the findings of this study, there was wide inadequate knowledge on what cervical cancer was and the cause hence women are less likely to do anything to prevent the disease if they do not know about it. While cervical cancer programs also require human resources and laboratory infrastructure, the World Health Organization has identified screening coverage as a crucial component of providing effective prevention (WHO, 2006)

An analysis of population-based surveys indicates that coverage of cervical cancer screening in developing countries is on average 19%, compared to 63% in developed countries, and ranges from 1% in Bangladesh to 73% in Brazil (Gakidou, Nordhagen and Obermeyer, 2008).

Some women believe that male circumcision is the number preventive measure for cervical cancer, but in the event that the men are not circumcised, they remain without an option to the prevention of the disease. In Zambia, there are strategies being implemented by the MoH and partners to support both primary and secondary prevention of cervical cancer. An HPV vaccination pilot was implemented in 2013-2016 to vaccinate grade 4 girls (or girls between 9-14 years) in 3 districts (Lusaka, Kafue and Chongwe). Scale-up of the vaccination program country-wide is yet to be implemented. According to May, (2016), strategies for prevention of cervical cancer focus on blocking infection through HPV vaccination (primary prevention) and detection and treatment of precancer to avoid development of cervical cancer (secondary prevention)

5.4 Perceptions on treatment.

Knowledge about cervical cancer disease and prevention was limited among the women as revealed by this study. This was also true with the understanding of the required treatment or treatment options for cervical cancer. Women's understanding of appropriate treatment for cervical cancer differed significantly with that required according to scientific evidence. Some women because of the limited understanding of the cause of the disease, believed treatment should also be supernatural through the witchdoctors or prayers. Their belief about appropriate treatment was consistent with their belief of what the cause was. In explanatory models of illness, the models of the cause of the disease affects belief of treatment and treatment outcomes. Treatment for cervical cancer depends on the stage of the disease at which the patient presents.

Scientifically proven types of treatment depending on the staging of the disease, range from surgery, Chemotherapy, Radiotherapy and brachytherapy. Before treatment is commenced, patients have to have the basic laboratory tests and have to meet the criteria for treatment depending on age, stage/spread of disease, physical fitness and laboratory tests.

CHAPTER SIX: CONCLUSION

Health seeking behavior should be measured by how much information that has been given out, how well that information has been received and the response to that information. Cervical cancer information should not be treated any different. Women will seek health care needs based on their interpretation and understanding of what the disease is, how severe it is and what they believe is the appropriate form of treatment. They will not seek any prevention measure if they are not informed. They will seek treatment from where they believe they will get help. The only known and cost-effective way to prevent cervical cancer among women who have been sexually exposed is early diagnosis and treatment. This significantly reduces mortality and morbidity among women.

There is need to ensure information dissemination is prioritized if women have to screen for cervical cancer. There is also need to ensure that information is disseminated in contextual appropriate ways for women to comprehend and act in response to the messages.

The main psychosocial barriers were fear/fatalism, denial, and Confucian thinking. Participants stated that medical advice and education would influence them most to undergo a Pap test. Recommendations were made to reduce certain barriers and to increase knowledge and motivations.

6.1 Implication of the study

This study should assist policy makers in ensuring that the messages they have developed and put across for the citizens are reaching them and they are comprehended. The policy makers should also ensure that the people whose messages are intended participate in the development of such messages for impact. The rights of these women (right to information, right to health and health care and right to live a life free of cervical cancer) should be considered when making the policies concerning educational programs and be within the context of culture norms.

This study served as a basis for a larger and wider study that can be generalized and explanatory models of cervical cancer from other parts of the country be understood by the researchers to inform the policy makers. This will aid in having a broader and more comprehensive picture of

the underutilization of the cervical cancer prevention services in the country despite all efforts that are placed to have women screen for the disease.

6.2 Recommendations

- There should be deliberate messages about cervical cancer prevention integrated into services that have reached the underserved women of Zambia to increase awareness about the disease and increase the level of behavioral change towards cervical cancer screening and prevention. This will ensure leverage of limited resources but have message reach the women in all parts of the country.
- Utilizing different information dissemination models that are appropriate and effective for particular regions of the country for example, use of electronic and print media targeting those in the urban settings that are able to read and comprehend while using print media with information translated into the local language for those in the rural areas that are able to read. The use of local authority structures like the traditional leaders, traditional healers for the dissemination of information for early screening, diagnosis and treatment to ensure messages are brought as close to the people as possible.
- Effective cervical cancer prevention messaging where the creation, development and production of Information and Education Communication (IEC) materials targets the end users and also involves them in the circle of development. The end user should contribute to the development of the IEC materials in order to maintain the appropriateness and effectiveness of the messages and pictorial components for the most impact.
- Cervical cancer has a devastating effect on families at large and hence the government of Zambia through the Ministry of Health and other line Ministries are required to ensure appropriate and adequate resources are directed to inform the people about the disease and have the people screen for cervical cancer. More screening centers should be scaled-up to all districts in the country. The opening of new sites should be coupled with serious education of the masses so that there is utilization of those centers opened.
- The use of cancer survivors and other women who have successfully screened as change agents to dispel many myths and misconceptions that deter women from screening for cervical cancer as a method can be explored.

6.3 Limitations of the study

- Firstly, the women that were interviewed had already been in contact with the health professionals hence there was health worker contamination of the women's knowledge of cervical cancer. The study hence relied on recalling the knowledge of the participants prior to contamination. A similar and larger study is therefore required in settings where women have the disease but have never been in constant contact with health professionals or have had their knowledge of the disease diluted by the knowledge of health workers.
- Generalizability of the findings of the study is a limitation for this. The study was conducted in one setting with a small sample size drawn though women came from various parts of the country other than Lusaka district alone as the hospital caters for all cancer cases in the country. The findings of the study may not be representative of other settings. Similar and larger studies are therefore necessary in other settings for comparability of research findings.
- Another limitation was using an interview in a cervical cancer ward as there were no private rooms provided. This could have had participants restrain from giving out further information for fear of being heard by other members of the ward. Respondents may not have been free to express their innermost feelings and express exactly their actual interpretation of the disease before they came in contact with a health care professional.
- The study during interviews face a challenge of eligible participants being quite mobile as they had to go for sessions of treatment in different parts of the hospital and when they get back to the ward, they would be weak and appear sicker than they went because of the treatment, hence the sampling procedure as was proposed could not be implemented. Women were interviewed based on the eligibility criteria and convenient sampling was implemented.

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APPENDICES

Appendix 1: Information sheet

Study title: Explanatory models of Cervical Cancer among women with a diagnosis of cervical cancer being cared for and treated at Cancer Diseases Hospital-Lusaka.

Principle investigator: **JANE MATAMBO**

Introduction: My name is Jane Matambo. I am a student at the University of Zambia pursuing a Master of Public Health, specializing in Health Promotion and Education. As part of the requirements for the awarding of this master's degree, I am conducting a research titled Explanatory models of Cervical Cancer among women accessing cervical cancer care and treatment in Lusaka.

I am requesting for your participation in the research study with the above title. You have been invited to participate in my study, but before participating in this study, I would like to explain to you the purpose, procedure, benefits and what I expect from you. Purpose of the research study: This study is part of the master's program for my training in public health, Health promotion and Education which I am doing with the University of Zambia. The main purpose of this study is as stated above and the study will also aim at further:

- To understand what women, believe cervical cancer is
- To find out from the women who have cervical cancer why they think the disease happened to them
- To find out from the women what they believe might have caused the cervical cancer?
- To get an understanding on what women who have cervical cancer think should be the appropriate treatment for them and for others with the diseases
- To get an understanding of what encourages women to seek or not to seek cervical cancer prevention services.

The participants in this study will be women aged between 25-59 years from within CDH who have been given a diagnosis of cervical cancer. The reason you are being asked to participate in the study is because you fit the description and the requirements of the study as a participant.

PROCEDURES: Participation in this study is voluntary; you have all the rights to decline participation, end interviews or discussions or decide to withdraw from the study at any time without a penalty. Once you sign the informed consent, the interview discussions with the principal investigator who will ask you questions on the above mentioned subject matter can commence. If you permit me, I will tape record the interview to help me pick all you will say. If not, I will ask you if it will be ok for me to write notes. The information from tape or notes will be typed in full, to help me fully understand what you will say. Your name will not be included in the tape and the typed documents as it will be kept secret.

RISKS/DISCOMFORT: There are no physical risks to participating in this research study. However, I recognize some information you may tell me or discuss during the interview may be personal or maybe sensitive. However, I would like to assure you that the information that I will get from you will not be shared with anyone outside the research team or to be used outside academic purposes.

BENEFITS: the participation in the study will help you learn more about what other women believe cervical cancer is and how it affects their wish to be screened for the cervical cancer. The benefits may not be direct; instead the information obtained from here will help policy makers and implementers to design sexual and reproductive health services which will benefit the other women.

PAYMENT: there is no payment of money in exchange for your participation. However, the information that will be obtained from this study will assist in understanding what different women think cervical cancer is and how this affects them in terms of seeking prevention services.

DATA CONFIDENTIALITY:

The information which will be collected from you will be treated with confidentiality unless permitted by yourself to use the information otherwise. The collected data will be locked in a

secure place. I will destroy all data within 3 years after typing the information. I will keep copies of typed information on CDs in case I have a problem with the computer.

What happens if you do not want to participate in the study?

You are free to decide whether you want to take part in the study or not. This will not bring any problem to you. Your access to treatment at the hospital will not in any way be compromised or denied.

Who to call if you have problems /questions

Jane Matambo
The P.O Box 34681,
Lusaka
Mobile No: +260-967 152 345
Email:janechintumatambo@gmail.com **OR**

The Chairperson
University of Zambia Biomedical Research Ethics Committee, Ridgeway Campus
P.O BOX 50110, Lusaka Tel: +260-1-256067

Appendix 2: Informed Consent Form

What do your signature (or thumbprint/mark) on this consent form mean?

Your signature (or thumbprint/mark) on this form means:

- You have been informed about the program’s purpose, procedures, possible benefits and risks.
- You have been given the chance to ask questions before you sign.
- You have voluntarily agreed to take part in this research study.

Print name of Participant	Signature of Participant	Date
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Print name of Person Obtaining	Signature of Person Obtaining Consent	Date
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Consent



Participant to mark a “left thumb impression” in this box if unable to provide a signature above

Appendix 3: Semi-Structured Interview Guide

The Semi Structured Interview is being guided by Arthur Kleinman's explanatory model of illness. (Kleinman, 1980).

1. What do you call the problem you are experiencing?
2. What do other community members call this problem?
3. What do you think has caused the problem?
4. Why do you think it started when it did?
5. What do you think the sickness does? How does it work?
6. How severe is the sickness? Will it have a long or short course?
7. What kind of treatment do you think the people with this problem should receive?
8. Do you know where others with the same problem go for their treatment?
9. What are the most important results you hope she receives from this treatment?
10. What do you think is the appropriate prevention for this illness?
11. What are the chief problems the sickness has caused?
12. What do you fear most about the sickness?
13. Did you believe there was need to screen for cervical cancer then?