SURVIVING CERVICAL CANCER: EXPERIENCES OF WOMEN IN THE ACCRA METROPOLIS

KAFUI ABRA HOBENU

(10256832)

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DECLARATION

This is to certify that this thesis is the result of research undertaken by Kafui Abra Hobenu towards the award of the Masters of Philosophy Degree in Nursing from the School of Nursing, University of Ghana, Legon. The research has been undertaken under the guidance and supervision of Dr. Lydia Aziato and Dr. Florence Naab, both of the School of Nursing, University of Ghana, Legon.

Signatories

KAFUI ABRA HOBENU ……………….. ………………….
(Candidate) Signature Date

DR. LYDIA AZIATO ………………… …………...…….
(Supervisor) Signature Date

DR. FLORENCE NAAB ………………… ………………….

(Supervisor) Signature Date

ABSTRACT

Studies from other countries have provided evidence that women with cervical cancer encounter physical, psychological and social consequences. However, in Ghana, not much is known about the experiences of such women. Thus, the study explored the physical, psychological, social and spiritual well-being of women with cervical cancer in the Accra Metropolis, using the Quality of Life Model Applied to Cancer Survivors as an organising framework to understand their survival experiences. An exploratory descriptive qualitative approach with purposive sampling technique was used to elicit information from 15 survivors receiving treatment at the Korle-Bu Teaching Hospital. Interviews were conducted face-to-face and audio taped. Interviews lasted between 45 to 90 minutes. Data was transcribed verbatim and analysed using thematic content analysis. Five major themes were derived and described as follows: physical well-being of women with cervical cancer; psychological well-being of women with cervical cancer; social well-being of women with cervical cancer; spiritual well-being and coping strategies of women with cervical cancer; and health system factors. The study found that survivors of cervical cancer experienced both disease related symptoms and treatment consequences which resulted in poor physical well-being. Survivors experienced anxiety, depression, suicidal tendencies as well as impaired relationships, isolation and financial difficulties. Most survivors received support from spouses, family, workplace and health workers. Survivors prayed and had hope in God as a way of coping. Survivors lacked knowledge on the disease symptoms. Again, health workers did not provide information to survivors on the disease and side effects of treatment. There were also instances of misdiagnosis. It was recommended that a multi-disciplinary approach be used in managing cervical cancer survivors. There should be public awareness creation on the early signs and symptoms of cervical cancer.

DEDICATION

I dedicate this work to my family without whom I could not have come this far; most especially to Edwin for his unflinching support in the care of our children Marvin and Mario when I was unavailable due to this work. To my sons Marvin and Mario; you two have been a source of strength to me in my trying moments when I was undertaking this study.

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LIST OF ABBREVIATIONS

ACS:	American Cancer Society
AMA:	Accra Metropolitan Area
APS-POQ:	American Pain Society-Patient Outcome Questionnaire
CCS:	Cervical Cancer Survivors
CDC:	Centre for Disease Control
CINAHL:	Cumulative Index to Nursing and Allied Health Literature
EBSCO:	Elton Bryson Stephens Company
ESAS:	Edmonton Symptom Assessment Scale
GLOBOCAN:	Global Burden on Cancer
HPV:	Human Papilloma Virus
IARC:	International Agency for Research on Cancer
KBTH:	Korle-Bu Teaching Hospital
NCI:	National Cancer Institute
PUBMED:	Public/Publisher MEDLINE
QoL:	Quality of Life
QoL-CS:	Quality of Life for Cancer Survivors
SSA:	Sub-Saharan Africa
UK:	United Kingdom
USA:	United State of America
WHO:	World Health Organization

CHAPTER ONE

INTRODUCTION

This chapter presents the background to the study, problem statement, purpose of the study, objectives, research questions, significance of the study and operational definitions.

1.1 Background to the Study

Cervical cancer is the second most common type of cancer affecting women worldwide. There are over 500,000 new cases and 250,000 deaths per year (Haghshenas et al., 2013). The American Cancer Society [ACS] (2015) has also reported that about 12,900 new cases of invasive cervical cancer were expected to be diagnosed in 2015 of which about 4,100 of such cases will die within the same period.

Significantly, cervical cancer has also been rated as the fourth most common cause of cancer related deaths among women worldwide as it results in about 274,000 deaths annually (Global Burden On Cancer [GLOBOCAN], 2014). According to the International Federation of Gynaecology and Obstetrics (FIGO), the development of cervical cancer is classified into four clinical stages (stages I-IV) with each of the stages having subdivisions. The cure or survival rate of cervical cancer decreases as the stages of the disease advance.

A key risk factor is the exposure to the Human Papilloma Virus (HPV) types 16 and 18 through sexual intercourse at an early age and/or having multiple sexual partners (ACS, 2015; Ago, Agan, & Ekanem, 2013; Anorlu, 2008; Eze, Emeka-Irem, & Edegbe, 2013; Malik, 2005; Okolo et al., 2010; WHO, 2015). Other risk factors include: smoking; immunosuppression; prolonged use of oral contraceptives (OCS); intrauterine device; three or more full-term pregnancies (ACS, 2015); as well as poverty (Denny, 2005; Eze, Umeora, Obuna, Egwuatu, & Ejikeme, 2012). Additionally, low literacy level has been identified as another risk factor (Eze et al., 2012; Lindau et al., 2002; Thulaseedharan et al., 2012). Vaccination against the HPV can, however, prevent cervical cancer. Although cervical cancer is the most prevalent cancer among women in developing countries, it is known to be the most preventable through screening and early treatment of pre-cancerous lesions (Murthy, Li, Azzam, Narasimhadevara, & Yezzo, 2010). According to the World Health Organisation (WHO, 2015), girls between the ages of 9 and 13 years should be vaccinated against the HPV virus before their first sexual encounter. Cervical cancer tends to occur in midlife mostly below the ages of 50 and rarely in women below age 20 (ACS, 2015; Anorlu, 2008; Eze et al., 2013). However about 15% of the cases do occur in women who are 65 years and above (ACS, 2015).

According to the World Health Organization [WHO] (2008), there were more than 530,000 new cases of cervical cancer worldwide and 275,000 deaths from cervical cancers. Over 90% of them were recorded in developing countries. In the WHO African Region Report, about 75,000 new cases were recorded in the same year and 50,000 women died of the disease. The report attributed this trend to factors such as poverty, poor medical infrastructure, and limited access to healthcare.

High incidence of cervical cancer has been reported in Africa at rates exceeding 50 per 100,000 population and age-standardized mortality sometimes exceeding 40 per 100,000 population. Cervical cancer remains a major public health problem in developing countries, especially in Africa where an estimated 53,000 women die of the disease each year (WHO, 2008). In view of the above reports, cervical cancer remains a major cause of morbidity and mortality among women in Africa (Sankaranarayanan, Budukh, & Rajkumar, 2006). Approximately 85% of all the cervical cancer related burden globally occur in developing countries such as Africa (Ferlay et al., 2010a).

In Africa, the Sub-Saharan region has the highest incidence of cervical cancer (Bruni et al., 2010). Cervical cancer has been identified as the second most frequently diagnosed cancer 80,400 cases) and the leading cause of cancer related deaths (53,300 cases) among women in Sub-Saharan Africa (SAA) (Ferlay et al., 2010b; GLOBOCAN, 2012; Jemel et al., 2011). It has been noted that most of the cervical cancer cases in SAA are diagnosed at the advanced stage (Eze et al., 2013).

In Ghana, the leading cause of cancer-related deaths among females has been attributed to cervical cancer (Parkin & Bray, 2006). Subsequently, the International Agency for Research on Cancer (IARC) estimated that in 2008, about 3,038 Ghanaian women developed cervical cancer of which 2,006 died (Adjei-Mensah, 2013).

Furthermore, in Ghana, the lifetime risk for women developing cervical cancer is about 2.2% and 2000 women are estimated to develop the disease yearly (WHO/ICO, 2007). From their study undertaken in Accra, Duda, Chen and Hill (2005) reported that among the gynaecological cancers diagnosed at any hospital in Ghana, cervical cancer accounts for about 60% and 70% of these cases are mostly diagnosed at the advanced stages. The incidence and mortality rates of cervical cancer in Ghana are among the highest worldwide (Lingwood et al., 2008; WHO/ICO, 2007). The rates have been on the increase in contrast to the decreasing trends in terms of incidence and mortality in the developed countries (Murthy et al., 2010).

A WHO/ICO (2007) report on Human Papilloma Virus (HPV) and cervical cancer statistics in Ghana predicted that by 2025, an estimated 5,000 new cases will be recorded of which 3,361 related deaths will occur annually. Statistics from the National Centre for Radiotherapy and Nuclear Medicine at the Korle-Bu Teaching Hospital revealed that from 2013 to 2014, 183 and 162 cases of cervical cancer were recorded respectively (Radiotherapy Centre, Korle-Bu, 2015).

Treatment options for cervical cancer include surgery, chemotherapy, radiation and hormonal-therapy. Side effects and the complications of the various treatment modalities cause significant changes in the patient physically, psychologically and socially (Vistad, Cvancarova, Kristensen, & Fossa, 2011). Physical side effects of cancer treatments include pain, changes in body image, skin changes, loss of appetite, weight gain, anaemia, diarrhoea, premature menopause, hair loss, fatigue, constipation, shortness of breath, mouth sores, delayed blood clotting time, vaginal dryness and shortness, sleep disturbances and infertility (Reis, Beji, & Coskun, 2010). Psychosocial effects of cancer treatment include distress, anxiety, depression, and loss of sexual desire (Reis et al., 2010).

In Ghana, the economic burden of cervical cancer on an average Ghanaian woman is high. Treating a woman with external beam radiation and brachytherapy costs about two thousand Ghana cedis (Gh¢ 2,000.00) while the cost of administering chemo-therapy is approximately one thousand, five-hundred Ghana cedis (Gh¢ 1,500.00) (KBTH-Radiotherapy Center, 2014). These are astronomical fees that the average Ghanaian woman may not be able to afford.

Coping strategies are thought to play an important role in managing the physical and psychosocial effects associated with a cancer diagnosis and treatment (Costanzo, Lutgendorf, Rothrock, & Anderson, 2006). In essence, effective coping may bring about positive Quality of Life (QoL) outcomes, and ineffective coping may lead to poor QoL outcomes among cervical cancer survivors. Coping by positive QoL could be done by reframing and accepting better social well-being and less distress. Some may become more religious and prayerful as a way of coping with the diagnosis of cervical cancer (Gonzalez et al., 2014; Walter, 2010).

It is shown that women with cervical cancer experience many problems. For instance, severe pain, vaginal bleeding, offensive vaginal discharge, and social isolation

(Ago et al., 2013; Eze et al., 2013; Van Schalkwyk, Maree, Deyer, & Wright, 2008). Although many studies have been done in developed countries, it appears there is no study on the experiences of women with cervical cancer in Ghana. As a result, a qualitative study is needed to provide detailed information on the lives of women with cervical cancer. The Quality of Life Model Applied to Cancer Survivors which has the physical, psychological, social and spiritual domains was adopted as an organizing framework to explore the experiences of Ghanaian women with cervical cancer in the Accra metropolis.

1.2 Problem Statement

Advanced presentation of cervical cancer occurs frequently in Ghana with an estimated 64.3% of affected women presenting at stages IIA – IVB of the disease (Duda et al., 2005; Nkyekyer, 2000). As a result, 3,038 Ghanaian women in 2008 were estimated to have developed cervical cancer of which 2,006 died (Adjei-Mensah, 2013). Despite the increased percentage of cervical cancer cases in Ghana, the experiences of these women are not known.

It is important to note that women with cervical cancer are confronted with physical, psychological and social problems (Vistad et al., 2011). The women mostly experience pain, profuse and offensive vaginal discharge and bleeding. These physical changes result in stigmatization, isolation from social milieu and loneliness (Maree et al., 2008; Van Schalkwyk et al., 2008; Wright, 2008). There are also feelings of fear, hopelessness, anger, shock and self-blame (Perrin et al., 2006). Other problems associated with cervical cancer are depression, sadness, embarrassment, and suspicion (Lin, Jeng, & Wang, 2011).

Studies from other countries indicate that aside from the disease process the side effects of the treatments cause many physical changes in the woman. These changes manifest in hair loss, weight and skin changes (Reis et al., 2010). These physical changes result in stigmatization, isolation and loneliness (VanSchalkwyk et al., 2008). Women with cervical cancer undergoing treatment may suffer infertility as a major side effect of some of the treatment modalities which may be a source of worry for some women (Carter, Chi, Brown, Abu-Rustum, & Aghanjanian, 2010).

Psychologically the woman may be anxious, depressed, distressed, sad and embarrassed (Lin et al., 2011). These psychological problems increase the patient’s desire to commit suicide (Shime & Hahm, 2010). Also, cost of treatment is a burden for most women as some of the women stop working temporarily (Kennedy et al., 2007; Wainer, Wallis, Dwyer, King, & Owada, 2012).

The disease process and the side effects of the treatment such as loss of fertility (Carter et al., 2010), depression and anxiety (Shime & Hahm, 2010) cause significant changes in women. These changes impact greatly on their daily lives as well as their relationships with their husbands/partners. Among women who are married or in active relationships, their husbands or partners are viewed as the main source of support (Barros & Lopez, 2007). In some instances it led to separation and divorce in the case of a married woman and for the unmarried ones, they lost their boyfriends (Baze, Monk, & Herzog, 2008; Maree, Masalo, & Wright, 2013).

In Africa, men view regular sex as a sign of good health and therefore expect their female partners whether sick or tired to perform their sexual obligations (Nelms & Gorski, 2006; O'Sullivan, Harrison, Morrell, Monroe-Wise, & Kubeka, 2006). The women may either be forced, or willingly allow the men to seek pleasure elsewhere or it leads to divorce or separation (Maree et al., 2013)

Statistics from the Radiotherapy Centre, Korle-Bu indicates that there were 183 cases of cervical cancer recorded in 2013 compared to 221 cases in 2012 (Radiotherapy Centre, Korle-Bu, 2015). Although there has been a reduction in cervical cancer cases, the focus of this study is not in the incidence. Several visits to the gynecological ward and the radiotherapy unit of the Korle-Bu Teaching Hospital (KBTH) and through interaction with the patients and the staff, the researcher noticed that women with cervical cancer have unexplored challenges and experiences.

For instance, the cost of treatment of cervical cancer is generally expensive and takes a financial toll on the patient and the family. Some patients stopped working temporarily due to the diagnosis (Kennedy et al., 2007). Others borrow or take grants in addition to support received from siblings (Maree et al., 2013).

Studies on cervical cancer in Ghana over the years have focused on prevention, screening and knowledge (Abotchie & Shokar, 2009; Blumenthal et al., 2007; Domfeh et al., 2008; Edwin, 2010). Therefore, this study explored the survival experiences of women with cervical cancer in the Accra Metropolis using the Quality of Life Model Applied to Cancer Survivors as an organizing framework.

1.3 Purpose of the Study

The purpose of the study was to explore the survival experiences of women with cervical cancer in the Accra metropolis.

1.4 Specific Objectives

The specific objectives are to:

1. Explore the physical well-being of women with cervical cancer;
2. Describe the psychological well-being of women with cervical cancer;
3. Examine the social well-being of women with cervical cancer; and
4. Describe the spiritual well-being of women with cervical cancer.

1.5 Research Questions

This study seeks to answer the following research questions:

1. What is the physical well-being of women with cervical cancer?
2. What is the psychological well-being of women with cervical cancer?
3. What is the social well-being of women with cervical cancer?
4. What is the spiritual well-being of women with cervical cancer?

1.6 Significance of the Study

It is expected that findings from this study would give health professionals valuable information that will guide the determination of the support that Ghanaian women with cervical cancer require. The findings of this study are also expected to bring to the notice of health professionals and the general public the concerns of the affected women so that interventions can be instituted to help improve their quality of life.

Policy makers in the health sector may use the findings to develop policies that will assist Ghanaian women with cervical cancer. The findings may be used for the development of training modules for health care professionals to improve the care of women living with cervical cancer. Furthermore, the findings of the study may contribute to the existing knowledge on the experiences of women living with cervical cancer.

1.7 Operational Definition of Terms

Cervical Cancer: abnormal growth of body cells in the cervix of the uterus.

Experiences: the situations that a woman living with cervical cancer goes through on a daily basis.

Women with cervical cancer: refers to women between the ages of 18 and 70 and diagnosed by a medical doctor to have a malignant growth at the mouth of the womb or uterus and has been receiving treatment at the Radiotherapy Centre, Korle-Bu Teaching Hospital at the time of data collection.

Quality of Life (QoL): refers to the impact of one’s disease and associated treatment on one’s ability to live a fulfilling life. This QoL may either be good, moderate or poor/impaired

Survivor: any woman who has been diagnosed with cervical cancer and is receiving treatment at the Radiotherapy Centre of the KBTH.

Physical Well-being: refers to one’s contentment with life as one experiences the signs and symptoms of cervical cancer and the side effects of treatment.

Psychological Well-being: refers to one’s contentment with one’s state of mind, ability to share feelings, fears and anxiety as one experiences the signs and symptoms as well as the side effects of treatment for cervical cancer or a positive mental state.

Social Well-being: refers to one’s contentment with one’s relationship with other people around her and her fiscal issues as one experiences the signs and symptoms of cervical cancer and receives treatment.

Spiritual Well-being: refers to a sense of inner peace and a search for meaning as one experiences the symptoms and side effects of the treatment of cervical cancer.

Coping strategies: are self-adopted approaches employed by women surviving cervical cancer in order to live a meaningful life as they experience the symptoms and treatment side effects.

CHAPTER TWO

THEORETICAL FRAMEWORK OF THE STUDY AND LITERATURE REVIEW

This chapter describes the QoL Model Applied to Cancer Survivors and relevant literature. The QoL model applied to cancer survivors was used to clarify concepts and associations and enabled the researcher to place a specific problem into an appropriate context. This chapter also reviewed relevant literature to the research problem. The literature was structured according to the objectives of the study.

The literature was retrieved from the following electronic databases: ‘HINARI’, ‘PUBMED’, ‘JSTOR’, ‘Science Direct’, EMBASE’, CINAHL, ‘Sage’, and ‘Wiley Online Library’ Google Scholar. For all these databases, the searches were limited to research articles published in the English language from 2000 to 2015. To increase the amount of relevant literature key words such as ‘cervical cancer’, were used together with ‘women experience’, ‘pain’, ‘fertility’, ‘sleep’, ‘psychological’, ‘social’, ‘coping’, ‘spirituality’, ‘surviving cervical cancer’, either individually or in combination in order to identify relevant studies.

2.1 Theoretical Framework of the Study (The Quality of Life Model Applied to Cancer Survivors)

Quality of life has been defined differently by various authors. The core of these definitions highlights the impact of one’s health on one’s ability to lead a satisfying life (Bullinger, Anderson, Cella, & Aaronson, 1993). Others view QoL to be an individual’s overall satisfaction with life and general sense of personal well-being (Schumacher, Olschewski, & Schulgen, 1991). Again, QoL is the state of well-being that is a combination of two components: the ability to perform everyday activities that reflect physical, psychological and social well-being; and patient satisfaction with levels of functioning and control of the disease (Ferrans & Powers, 1992). Another school of thought considers the concept of QoL as “the subjective and personally derived assessment of overall well-being that results from evaluation of satisfaction across an aggregate of personally or clinically important domains” (Bishop, 2005, p.7). Carr, Gibson, and Robinson (2001) claim that QoL is an all-inclusive concept involving the effect of disease or impairment on one’s normal life. Consequently, QoL is the appraisal of one’s current state against some standard (Cella & Tulsky, 1990).

The Quality of Life Model Applied to Cancer Survivors was developed by Ferrell, Hassey Dow and Grant (1995) and modified in 1999. This model encompasses four main domains/dimensions being the physical, psychological, social and spiritual well-being. Subsequently the domains are discussed.

Physical Well-being and Symptoms

The physical well-being is the control or relief of symptoms and maintenance of function and independence. In the model, the physical well-being and symptoms domain comprises of functional activities, strength/fatigue, sleep and rest, overall physical health, fertility and pain. Cancer and/or its treatment have a lot of effect on the survivor. Generally, the common distressing acute physical side effects of cancer treatment are bone marrow depression, hair loss, mucositis, skin changes, nausea and vomiting, and nutritional changes; and these are said to subside within a few weeks or months after the completion of therapy (Rhodes, Johnson, & McDaniel, 1995). Pain and fatigue are the most common late-effects affecting the physical well-being of patients. Pain is common in advanced disease and it is related to bone metastasis and compression of adjacent nerves, vascular structures, and soft tissue. Pain may also result from incisional pain, paraesthesia, oedema, and phantom limb sensations. Fatigue is a prevalent and troubling symptom of cancer treatment that has been overlooked because it is not considered life-threatening (Winningham et al., 1994). Likewise, the impact of pain on QoL, and fatigue produces severe disruption to patients’ ability to function in all aspects of life. Additionally, menopausal symptoms have been identified in long-term cancer survivors.

Psychological Well-Being

Psychological well-being is the effort to maintain a sense of control in the face of life-threatening illness evidenced by emotional distress, altered life priorities, fear of the unknown, and positive life changes. In the model, this domain is made up of the following components: control, anxiety, depression, enjoyment/leisure, fear of recurrence, cognition/attention, distress of diagnosis and control of treatment. In this domain, the most challenging changes affecting QoL include: anxiety, fear of recurrence, second malignancies, or metastatic disease, concern over future tests and distress over recall of the initial cancer treatment (Boman & Bodegard, 1995). The changes are manifested by anxiety, mood swings and depression.

Social Well-Being

Social well-being is concerned with the effort to deal with the impact of cancer on individuals, their roles, and relationships. In the model, this domain is made up of family distress, roles and relationships, affection/ sexual function, appearance, enjoyment isolation, finance and work. Quality of life concerns include issues related to roles and responsibilities; family issues; sexual and marital problems; adjustment of children; and work-related issues such as concerns over cancer disclosure, stigma, re-entry into the workplace, changes in work priorities, discrimination, health insurance and issues of support (Halstead & Fernsler, 1994).

Spiritual Well-Being

Spiritual well-being involves the ability to maintain hope and derive meaning from the cancer experience which is characterised by uncertainty. In the model, this domain comprises of meaning of illness, religiosity, transcendence, hope, uncertainty and inner strength. Some studies have associated religiosity and spiritual support with recovery from breast cancer. A sense of hopefulness and having a purpose in life also influences spiritual wellbeing. Spiritual concerns most often arise after cancer treatment has ended (Highfield, 1992; Kahn & Steeves, 1993).

The key features of QoL are multidimensional and subjective. The multidimensionality aspect refers to the domains (physical, functional/role, emotional/psychological and social well-being). Subjectivity of QoL on the other hand, refers to people's perspective of their illness and treatment, expectation of self and estimation of risk or harm (Cella, 1994). In health research, the concept of QoL may also be viewed objectively. However, the choice between subjective or objective QoL depends largely on the importance, appropriateness and the nature of the research questions that need to be answered. In health, QoL is regarded as a basis for making decisions regarding healthcare.

In cancer, quality of life has been defined as a personal sense of well-being encompassing a multidimensional perspective that generally includes physical, psychological, social, and spiritual dimensions or domains (Dow, 1992; Winningham et al., 1994). The QoL among cancer survivors and the means to measure their QOL is a necessity because of improved cancer treatment and supportive care which have resulted in an extended length of survival (ACS, 1995). Also, the emergence of a national forum where cancer survivors have the opportunity to state their concerns triggered debates in the spheres of politics and health policy (Leigh & Logan, 1991). Below is a diagram depicting the various components of the QoL model by Ferrell, Grant, and Hassey-Dow (1999) applied to cancer survivors.

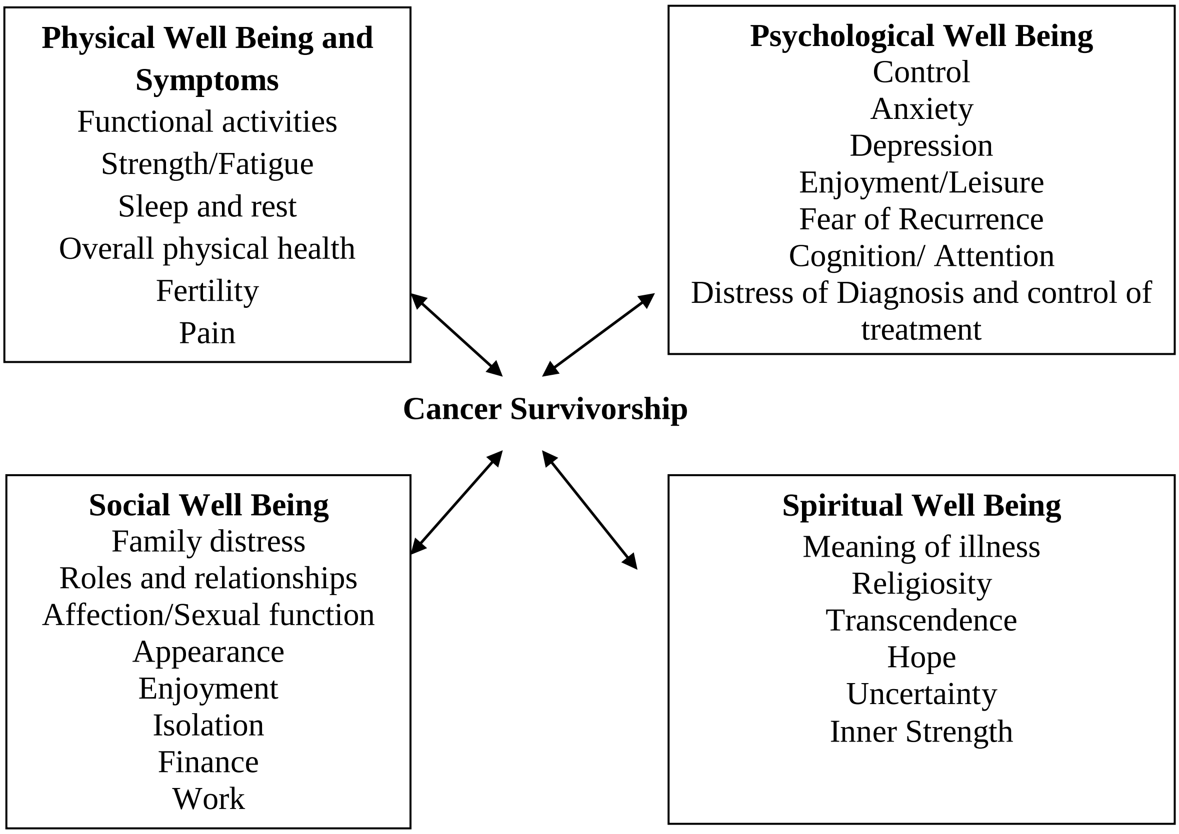

Figure 2.1: ***Quality of Life Model Applied to Cancer Survivors***
Source: Adopted from Ferrell, Grant and Hassey Dow (1999)

2.1.1 Model Modification

The QoL model has been modified to suit different cancer presentations. Although there are modifications in the models, the four key dimensions of physical, psychological, social and spiritual remain unchanged. However, there are slight variations in the constructs that make up each domain. For instance, the Quality of Life Model applied to cancer survivors which Ferrell et al. developed in 1995 was modified in 1999 by the City of Hope Beckman Research Institute in consultation with Ferrell, Grant and Hassey-Dow and was renamed as Quality of Life Model Applied to Cancer Survivors. Although the key dimensions remain the same, slight changes were made in all the domains. In the physical domain of the first model, appetite, constipation, and nausea were included as factors influencing physical well-being. However, the modified model does not have these constructs.

Also, the ‘Functional Ability’ in the physical domain was revised as ‘Functional Activities’ in the modified model of 1999. In the psychological domain, the 1995 model had ‘pain distress’, ‘happiness’ and ‘overall perception of QoL’ being part of the constructs. However, in the modified version of 1999, they were eliminated. Furthermore, the social domain of the first model had ‘employment’ as a construct but has been replaced with ‘work’ in the modified model developed in 1999. Again in the social domain, the 1995 version of the model does not have ‘Enjoyment’ as a construct but it is part of the 1997 model. Lastly, the spiritual domain was also modified. The first model of 1995 had ‘Positive Change’ as a construct but this was removed from the 1999 version.

Out of the main Quality of Life Model Applied to Cancer Survivors, Ferrell and her colleagues developed various models with the same concept that are peculiar to breast cancer survivors, ovarian cancer survivors, caregivers, patients with fatigue, pain, ostomy, and bone marrow transplants. All these models have the four key domains of physical, psychological, social and spiritual.

This study used the modified version as an organising framework to understand the QoL of cervical cancer survivors.

2.1.2 Overview of QoL of Cancer Survivors

Cancer survivors took part in clinical trials and advocated for the needs of other cancer survivors. Further, some of the cancer survivors published their first hand experiences with cancer in both lay and professional literature (Bushkin, 1993). These steps by earlier survivors served as a source of inspiration and information for others facing similar circumstances. These factors played a major role in focusing attention on the broader needs and concerns of adult cancer survivors in the long term. To this effect, the

Quality of Life for Cancer Survivors (QoL-CS) tool was developed to measure the QoL of the survivors and also to evaluate for future use of the QoL long-term; and identify potential areas for education, counselling and support. During the development of the tool, qualitative methods using interviews and focus groups were employed to derive rich content (Hassey Dow & Ferrell, 1994).

Cancer survivorship has been explained quite differently by many researchers. For example, many consider a person to be a survivor from the moment of diagnosis through the balance of his or her life (CDC, 2011). However, the American Cancer Society (2012) broadly defines a cancer survivor as anyone who has been diagnosed with cancer, from the time of diagnosis to the time of initial treatment and the transition from treatment to extended and long-term survival. Beyond the above definitions, the National Cancer Institute [NCI] (2004) considers an individual as a survivor from the time of diagnosis, through the balance of his or her life.

A cancer survivor in this study is any woman who has been diagnosed with cervical cancer and is currently receiving treatment.

2.1.3 Justification and Relevance of the Model to the Study

In Africa, the researcher is not aware of any study that employed the Quality of Life Model Applied to Cancer Survivors (QoL-CS) for cervical cancer. In this study, the modified (1999) model was used to get first-hand information on the experiences of women with cervical cancer (women who are currently with the disease and are receiving treatment) since the main domains of the model and their components are relevant to cervical cancer survivors.

In the current study, the physical well-being focused on the fertility, sleep and rest, strength/fatigue and functional activity experiences of women with cervical cancer. Other physical concerns of the women that were not in the QoL model were also explored to understand their survival experiences.

In exploring the psychological well-being of women with cervical cancer, the study focused on anxiety, depression, enjoyment/leisure, cognition/attention and distress of diagnosis of the QoL model. Additionally other key areas that influenced the psychological well-being of the women were considered.

For the social well-being, family distress, roles and relationships, affection/sexual function, appearance, isolation, finance and work components of the model were used to understand the social surviving experiences of women with cervical cancer. In addition, essential aspects that impacted upon the social well-being of the women were explored to appreciate the social well-being of the women in totality.

Finally, this study explored the meaning of illness, religiosity, hope, uncertainty and inner strength to understand the spiritual well-being of women with cervical cancer.

2.2 Literature Review

Relevant literature reviewed was organized under the following captions:

- Physical Well-being of Women with Cervical Cancer

- Psychological Well-being of Women with Cervical Cancer
- Social Well-being of Women with Cervical Cancer
- Spiritual Well-being of Women with Cervical Cancer

2.2.1 Physical Well-being of Women with Cervical Cancer

At the advanced stages of cervical cancer, women present with pain, continuous vaginal bleeding in between their menstrual periods, bleeding after sexual intercourse and offensive and profuse vaginal discharges (Maree et al., 2013). The symptoms affect the physical well-being of women with cervical cancer.

2.2.1.1 Pain

Pain has been identified in a number of studies as one major physical challenge that women with advanced cervical cancer experience (Maree et al., 2013; Reis et al., 2010; Wainer et al., 2012). The pain associated with cancer may be due to a lesion, direct tissue damage (Levy, Chwistek, & Mehta, 2008; Portenoy, 2011) and bone metastasis (Thanapprapasr et al., 2010). Cervical cancer pain was identified by these authors with peculiarities. For instance, Wainer et al. (2012) in their study interviewed 25 women with gynaecological cancers in Australia. The findings indicated that pain in the bladder, lower abdomen, bowel, leg pain, chest and painful sexual intercourse were the initial complaint of the women. Other studies also identified abdominal pain, severe leg and back pain (Maree, Langley, & Nqubezelo, 2014; WHO, 2006) as signs of late cervical cancer while severe back pain is considered as being one of the presentations of very late invasive cervical cancer (WHO, 2006).

Reis et al. (2010) in their study elicited information from 100 women with various gynaecological cancers (vulva, endometrial, cervical and ovarian) on their quality of life and sexual functioning in Istanbul, Turkey. The Quality of Life - Cancer Survivors (QOL-

CS) instrument was used to evaluate their quality of life. About 30 of the women were randomly selected and interviewed to gain an insight into their sexual functioning and health. The quantitative data from the study suggested that on average the women experienced high levels of pain. Considering the physical well-being of women with gynaecological cancers, women with cervical cancer had poor quality of life. Even though the quantitative data in the mixed method approach by Reis et al. (2010) could not provide further information on the pain, the qualitative data described the location of the pain (vagina) and its nature (burning, and as though a knife is being used to cut through a wound).

Most women in the advanced stage of cervical cancer develop pain in the area referred to as the flank or leg (Ago et al., 2013). In a survey of terminally ill patients in five countries in Africa – Uganda, Ethiopia, Tanzania, Zimbabwe and Botswana, the key need expressed by the patients was pain relief (Sepulveda, Habiyambere, & Amandua, 2003). In another study aimed at comparing the concerns of terminally ill patients in a developed country (Scotland) and an African country (Kenya), it was revealed that the main concern of the Scottish patients was the emotional pain of facing death, while for their counterparts in Kenya it was physical pain (Murray, Grant, & Grant, 2003).

The pain experienced by the cancer survivors is managed with analgesics. The use of analgesics for pain management in cancer patients has been in line with WHO’s analgesics ladder which can result in approximately 75% of patients attaining good pain control. However, poor cancer pain management has been acknowledged by WHO as a worldwide health problem (Li et al., 2013; Zhao, Zhou, & Song, 2007). In many cases, analgesics do not completely relieve cancer pain (Basbaum & Julius, 2006; Gauthier et al., 2009; Rhiner, Palos, & Termini, 2004). A number of studies have identified the use of music therapy as a non-pharmacological pain management approach for cancer patients. In their report, they mentioned a decrease in pain attributed to music therapy (Colwell, Edwards, Hernandez, & Brees, 2013; Gutgsell et al., 2013; Whitehead-Pleaux, Baryza, & Sheridan, 2006; Whitehead- Pleaux, Zebrowski, Baryza, & Sheridan, 2007). Similarly, a study in Southern Taiwan among cancer patients showed that most of the participants used music to both relax and distract themselves from the cancer pain (Huang, Good, & Zauszniewski, 2010).

Vistad et al. (2011) conducted a quantitative study in Norway to describe chronic pelvic pain and associated variables in advanced cervical cancer survivors (ACCSs). Findings suggested that pain has a significant impact on QoL and the day-to-day well-being of the survivors.

Physical well-being and functional well-being have been studied in relation to QoL (Cramarossa et al., 2013; Pasek, Suchocka, & Urbanski, 2012). Physical well-being predicted the overall QoL among women with cervical cancer (Cramarossa et al., 2013). Pain was found to negatively influence the physical well-being of women with cervical cancer and women with an advanced stage of the disease had poor QoL.

2.2.1.2 Gynaecological Challenges

Offensive vaginal discharge and bleeding as well as other vaginal changes such as vaginal dryness and atrophy are experienced by women with cervical cancer (Bukovic et al., 2008; Cleary & Hegarty, 2011; Lammerink, de Bock, Pras, Reyners, & Mourits, 2012). Some related studies (Herzog & Wright, 2007; Maree et al., 2013; Stead, Fallowfield, Selby & Brown, 2007), also reported that women with cervical cancer experience vaginal alterations. Vaginal bleeding and offensive vaginal discharges are common physical challenges of cervical cancer survivors (Maree, 2013; VanSchakwyk et al., 2008; Wainer et al., 2012). Other groups of researchers (Ago et al., 2013; Eze et al., 2013; Langley & Mary, 2012), in their related studies also reported that vaginal bleeding and / or offensive vaginal discharge were the most frequently reported symptoms in women with advanced cervical cancer.

Some women bled heavily in clots in addition to offensive vaginal discharge (Van Schalkwyk et al., 2008). In the study of Maree et al. (2013, p.462) a cervical cancer survivor, in an attempt to describe her vaginal discharge, likened the smell to a *"dead rat"* and had to open doors and windows for the smell to minimize and used pieces of cloths to soak the offensive discharge.

In South Africa, cervical cancer survivors revealed that profuse vaginal bleeding was problematic as they had to buy baby diapers to manage the bleeding. Some of the survivors further stated that the bleeding sometimes become so severe as to warrant blood transfusions (Maree et al., 2014). Similarly, a number of studies also reported vaginal bleeding and offensive vaginal discharge as common presenting complaints in varying frequencies of women with advanced cervical cancer in Nigeria. The researchers reported that the abnormal vaginal bleeding was in the form of post-coital, inter-menstrual, or post-menopausal bleeding (Eze et al., 2013; Ikechebelu, Onyiaorah, Ugboaja, Anyiam, & Eleje, 2010; Oguntayo et al., 2011; Umezulike, Tabansi, Ewunonu, & Nwana, 2007). The vaginal bleeding has been found to negatively affect the QoL of the cervical cancer survivors (Vaz et al., 2007).

It has also been reported that a significant number of pre-menopausal cervical cancer survivors experience infertility as a result of their treatment. As reported by the American Cancer Society, cancer treatment can negatively impact upon female fertility through the surgical removal of all or part of the reproductive organs (ACS, 2013; Ashing-Giwa et al., 2006). In the literature, infertility has been identified as one of the primary concerns for cancer survivors, although it may seem secondary in light of a life-threatening illness. Nonetheless, survivors have reported that the loss of fertility as a result of cancer treatment can be as disturbing as facing the cancer itself (Gardino, Rodriguez, & Campo-Engelstein, 2011; Gorman, Bailey, Pierce, & Su, 2012; Nieman et al., 2006; Schover et al., 2014). In another study on the effect of cancer treatment on female fertility, it was disclosed that aggressive chemotherapy and radiotherapy in young patients with cancer has greatly enhanced the life expectancy of these patients, but these treatments often cause infertility because of the massive destruction of the ovarian reserve resulting in premature ovarian failure (Maltaris et al., 2007).

Carter et al. (2005) in a cross-sectional study of women who have undergone treatment for gynaecologic cancer (**N**=20) suggest that significant numbers of women have lost their fertility as a result of their cancer treatment. In African, child bearing is valued and regarded as one of the key responsibilities of women (Hollos & Larsen, 2008). Therefore, a woman’s inability to meet this cultural expectation is a source of stress for the family. For instance, infertility has been cited in a number of studies to have been the main cause of divorce among married couples in the western world (Behboodi-Moghadam, Salsali, Eftekhar-Ardabily, Vaismoradi, & Ramezanzadeh, 2013; Obeidat, Hamlan, & Callister, 2014) and in the African society (Dyer, Abrahams, Mokoena, Lombard, & van der Spuy, 2005; Hollos & Larsen, 2008). Infertility has been identified as a major complication of cervical cancer treatment and this can be temporal or permanent (Baze et al., 2008; Reis et al., 2010; Stead et al., 2007).

The issue with infertility has been reported to have a grave impact on cervical cancer survivors. The uterus has a symbolic importance to the concept of femininity (Juraskova et al., 2003). Gynaecological cancer surgery means loss of the uterus and ovaries. This implies that the women lose their femininity, motherhood and sexuality. The loss of femininity has been reported by gynaecological cancer patients in both quantitative (Chan et al., 2001; Tornatta, Carpenter, Schilder, & Cardeness, 2009) and qualitative studies (Juraskova et al., 2003). In a related study, it was reported that women who linked the uterus and the ability to bear children with feelings of femininity reported lower self-esteem and a more negative body image following treatment (Carter et al., 2005).

Reis et al. (2010) reported that women from Muslim society identify their reproductive organs, especially the uterus, with their sex lives as the uterus remains the symbol of femininity, sexuality, fertility, and motherhood. A woman without a uterus is regarded as an *"empty sack or a man"* (p.142). Women who were childless in the study were asked how the cancer and the treatment has affected their fertility and their life: one of the women, 28 years old, stated that she would not have been sad if she had at least a child. A participant used words such as *'useless'*, *'incomplete'*, *'disliked'*, *'valueless'* to describe her loss of fertility (p.143). The women felt marked because they are infertile. Baze et al. (2008), in her personal account of her experience with cervical cancer reported her wish to have her own child but finally lost her fecundity to the treatment of her cervical cancer. Studies conducted by Reis et al. (2010), Stead et al. (2007) and the personal account of Baze et al. (2008) illustrate the possible loss of fertility a woman is likely to encounter in her course of treating cervical cancer.

Ashing-Giwa and team in their multi-ethnic study revealed cervical cancer survivors (CCS) expressed feeling damaged and worn out after the diagnosis and were extremely concerned with illness and treatment effects on fertility (Ashing-Giwa et al., 2004). Loss of fertility was particularly distressing for women who had not yet had children. However, according to Stead et al. (2007) in a study among gynaecological cancer patients, the women perceived the issue of infertility differently depending on their child-bearing needs. It was revealed that women who have completed their child-bearing activities were not concerned about the loss of their child-bearing status but were concerned about not being able to care for their family. Conversely, women who still wish to have children felt as though they were not women any more. Another gynaecological challenge faced by cervical cancer survivors reported in literature has to do with alteration in vaginal length, calibre and elasticity as a result of treatment. Radical hysterectomy is noted to result in a shortened vagina (Quinn, 2007; Stead et al., 2007). Radiation therapy has a fibrotic effect on tissues causing thickening and lack of elasticity. This results in dyspareunia together with lack of lubrication during sexual arousal resulting in vaginal irritation, vaginal atrophy, vaginal dryness, vaginal stenosis, and sexual arousal difficulties (Donovan et al., 2007; Frumovitz et al., 2005; Stead et al., 2007).

2.2.1.3 Impaired Sleep

Sleep disturbance has also been identified as a key consequence as a patient travels along the trajectory of cancer survivorship in a number of studies (Gibbins et al., 2009; Palesh et al., 2010; Parker et al., 2008; Stepanski et al., 2009).

According to Mystakidou et al. (2007), sleep disturbances in cancer patients may be attributable to many, varied, and complex interacting factors such as pain, treatment side effects, and psychological causes. Findings from an exploratory and descriptive study indicate that the main cause of poor sleep quality among cancer patients was pain because cancer pain during the night trigger frequent nocturnal awakening (Furlani & Ceolim, 2006). In South Africa, underprivileged women with cervical cancer reported impaired sleep due to unrelieved pain (Maree et al., 2014). Similarly, studies in Western countries established sleep disturbance among cervical cancer survivors (Ashing-Giwa et al., 2004; Distefano et al., 2008; Griemel, Winter, Kapp, & Haas, 2009; Zeng, Li, & Loke, 2011). A number of studies also cited insomnia as a common problem among survivors of gynaecological cancers (Akyuz, Guvenc, Ustunsoz, & Kaya, 2008; De Groot et al., 2005; Ekwall, Ternestedt, & Sorbe, 2003).

2.2.1.4 Gastrointestinal Disorders

Advanced stages of cancer affects the eating pattern of patients (Bell, Lee, & Ristovski-Slijerpcevic, 2009; Hopkinson, Wright, & Corner, 2006). Nutritional symptoms such as anorexia and dysphagia have also been revealed by a group of researchers as conditions that prevent cancer patients from eating adequately (Kubrak et al., 2010). Loss of appetite is a sign of progressive disease among the cancer population, as well as the outcome of toxic cancer therapies (Poole & Froggatt, 2002). Studies among cervical cancer survivors also reported that loss of appetite experienced by these women affect their QoL negatively (Krikeli et al., 2011; Zeng et al., 2011). Studies also revealed that the treatment options and their side effects as well as complications also led to some gastrointestinal challenges (Baze et al., 2008; Hsu et al., 2009; Reis et al., 2010; Wainer et al., 2012).

There are various treatment modalities that may be chosen singularly or in combination for the management of the disease and this is determined by the stage at which the woman is diagnosed. The treatment options available are surgery, radiotherapy, chemotherapy, and brachytherapy with their varied side effects. Any treatment of choice for cervical cancer poses some form of physical challenge (Baze et al., 2008; Hsu et al., 2009; Reis et al., 2010; Wainer et al., 2012). Patients treated for gynaecologic cancer experience physical symptoms such as nausea and vomiting (Akyuz et al., 2008; De Groot et al., 2005; Ekwall et al., 2003). Studies on cervical cancer survivors in some Western countries reported nausea and vomiting as treatment side effects (Ashing-Giwa et al., 2004; Distefano et al., 2008; Griemel et al., 2009; Zeng et al., 2011). A related study reported that, in addition to the nausea and vomiting, treatment of cancer with chemotherapy and radiotherapy causes diarrhoea (Perwitasari, Gelderblom, Atthobari, Mustofa, & Dwiprahasto, 2011). However, other studies cited diarrhoea as the most common side effect of chemotherapy (Arnold et al., 2005; Benson, Ajani, & Catalano, 2004; Maroun et al., 2007; Sharma, Tobin, & Clark, 2005). Diarrhoea during chemotherapy has been reported with an incidence ranging between 30% and 80%, with mostly one third of the patients experiencing the severe form (Arbuckle, Huber, & Zacker, 2000; Benson et al., 2004).

The gastrointestinal side effects of cervical cancer treatment negatively impacted on the survivors' QoL. A study in Sweden among women receiving chemotherapy showed that nausea and vomiting, which were the most distressing side effects experienced by the women, had a negative impact on their daily lives as it affected their food intake, weight and sleep pattern (Bergkvista & Wengstrom, 2006). Similarly, a study in Greece emphasised the impact of radiotherapy and radio-chemotherapy on the QoL of cervical cancer survivors. The findings indicated that survivors who received only radiotherapy had increased nausea and vomiting which led to decreased QoL for those survivors than for survivors who received radio-chemotherapy (Krikeli et al., 2011).

2.2.1.5 Body Disfigurements

Advanced cervical cancer and its treatment affect the physical appearance or body image of the women. In view of this, a number of studies on cervical and gynaecological cancers survivors observed that some physical changes such as change in weight, hair loss and scarring have a negative effect on their body image (Akyuz et al., 2008; Ashing-Giwa et al., 2004; Baze et al., 2008; Burns, Costello, Ryan-Woolley, & Davidson , 2007; DeFrank, Bahn, Stein, & Baker, 2007; Eze et al., 2013; Maree et al., 2014; Reis et al., 2010). Cancer survivors experience a change in body when receiving treatment. However, not all these changes are visible. When the changes are visible, the cancer survivors try to conceal them in many ways such as under clothes and wigs (Rasmussen, Hansen, & Elverdam, 2010).

The skin is the main route of administration of chemotherapy and radiotherapy. Skin reaction has been cited as one of the most common side effects of chemotherapy and radiotherapy (Ryan et al., 2007). There is undoubted evidence from some studies that emitting ionizing radiations from radiotherapy and the lethal agents from chemotherapy are the major causes of skin reactions in cancer patients during treatment (Ryan et al., 2007). Hyperpigmentation, hypopigmentation, erythema, moist desquamation, necrosis, and atrophy are dermatological manifestations commonly cited by cancer patients receiving chemotherapy and radiotherapy (Alley, Green, & Schucter, 2002).

A study on patients' late effects of gynaecological cancer treatment in the United States showed that of the total 390 gynaecological cancer survivors sampled for the study, 92 women in the cervical cancer group who had undergone various treatments reported changes in texture or colour of radiated skin (Grover et al., 2012).

2.2.1.6 Fatigue

Fatigue has been reported to be one of the most common and troubling symptom associated with cancer and its treatment (Karakoc & Yurtsever, 2010; Pleun, de Klerk, Timman, Hinz, & van der Rijt, 2012; Seo, Oh, & Seo, 2010). A study in Turkey by Karakoc and Yurtsever (2010) found that 93% (N=71) of women reported fatigue as treatment related. The investigators identified two types of fatigue (general and physical). They described general fatigue as feelings of tiredness whereas physical fatigue is about the physical sensations of tiredness.

Another group of researchers also reported that patients with cancer experience fatigue which is likely to affect their ultimate functional activities. Although their study is quantitative in nature, it somehow provided an insight into the different types of fatigue that a patient with cancer is likely to experience. They identified three levels of fatigue, namely: reduced activity, reduced motivation and mental fatigue. To these researchers, reduced activity (being the first level of fatigue) is concerned with a decrease in the level of activity. Reduced motivation (the second level of fatigue) refers to the lack of motivation to do things; and mental fatigue (being the final level of fatigue) is concerned with the difficulty in staying focused (Pleun et al., 2012).

Fatigue is highly prevalent among the cancer population and has a great impact on their lives. The cancer-related fatigue experience is subjective and multidimensional. Employing a qualitative approach, some cancer survivors describe fatigue as unforeseen because it is much more than just being tired (Wu & McSweeney, 2007). Furthermore, the study revealed that the participants were depleted of energy; had impaired mobility; and reported an unusual need for rest. The fatigue experience was overwhelming, continuous and unrelieved by rest. The study additionally stated fatigue to be a holistic phenomenon. This holistic phenomenon pertaining to the nature of fatigue was explained as having an impact on all aspects of the lives of the participants. The relationship between participants and their children, husbands and friends were affected (Wu & McSweeney, 2007). Other authors mentioned in their respective studies that the fatigue experience influenced patients' activities and roles within their families and the wider social contexts (Barsevick, Whitmer, & Walker, 2001; Gledhil, 2005). Due to fatigue, survivors had to carry out activities at a slower pace, took breaks in between activities or involved themselves in less demanding activities (Spichiger, Rieder, Muller-Frohlich, & Kesselring, 2012; Wu & Mc Sweeney, 2007).

Treatment-related side effects (Barker, Routledge, Farnell, Swindell, & Davidson, 2009; Barnas, Skret-Magierlo, Skret, & Bidzinski, 2012; Bjelic-Radisic et al., 2012), cervical cancer (Barnas, 2012) and advanced stage of disease (Vaz et al., 2007) have been found to negatively affect the physical well-being and QoL of women with cervical cancer.

In summary, the review of literature on the physical well-being of women diagnosed with cervical cancer and who are receiving treatment indicated that women with cervical cancer generally have poor physical well-being.

2.3 Psychological Well-being of Women with Cervical Cancer

The literature review under psychological well-being focused on anxiety, depression and lack of information, distress of diagnosis, cognition/attention, fear of death, and suicidal tendencies. Subsequently, the psychological concerns of women with cervical cancer are presented.

2.3.1 Anxiety, Depression, and lack of information

It is important to note that the physical challenges of a woman with cervical cancer in turn affect the psychosocial aspect of her life. This is embedded in the QoL-CS model (Ferrell et al., 1999). Feelings of depression, anxiety, fear, confusion, disphoria, hopelessness, embarrassment, frustration, self-blame, altered self-esteem, distress and anger are common psychological experiences of women with cervical cancer (Baze et al., 2008; Herzog & Wright, 2007; Lin et al., 2011; Shim et al., 2011; Stead et al., 2007). Similarly, Sharp, Carsin, and Timmons (2013) argued that cancer diagnosis and treatment have adverse psychological effects on the patients which manifest in the form of depression, anxiety and distress. Cancer diagnosis and treatment are associated with the risk of depression due to lower income status at diagnosis coupled with the care of children.

Furthermore, anxiety was found to be significantly associated with cancer diagnosis and treatment especially among patients with low education and no private health insurance (Sharp et al., 2013). Symptom burden has been identified as a main source of depression and anxiety among cancer patients (Nuhu, Odejide, Adebayo, & Yusuf, 2008). Beyond that, the association of pain and psychological morbidity has been established in some studies among cancer survivors. In those studies, the researchers stated that increase in cancer pain is related to increase in anxiety (Ko, Seo, Youn, Kim, & Chung, 2013; Lekka et al., 2014). In addition to that, Nuhu et al. (2008) in their study determined the prevalence of pain and its psychological and physical effects among 210 patients with various cancers including cervical cancer (n=59). The investigators reported that there is a direct link between anxiety and depression as a result of severe pain in advanced disease.

According to Stafford and Judd (2011), depression has widely been reported among gynaecologic cancers survivors. Akyuz et al. (2008) also observed that gynaecological cancer survivors experience psychological problems such as stress, fear, and anxiety because of the radiation treatment and chemotherapy. The psychological impact of cervical cancer identified among survivors in China included anxiety, depression, irritability, a fear of cancer recurrence, feeling of guilt due to burdening of the family, and worrying about the disease (Zeng et al., 2011). Furthermore, participants in the study of Wenzel et al. (2005) disclosed being sad as a result of their inability to bear their own biological children. The women were also reported to be frustrated and mourned over their loss of fertility. In addition to that, cervical cancer survivors in a quantitative study were reported to experience anxiety, dysphoria, anger and confusion. The investigators concluded that cervical cancer survivors seem to be more susceptible to negative mood difficulties. Therefore, health care professionals should focus on the psychological well-being of gynaecologic cancer survivors (Bradley, Rose, Lutgendorf, Constanzo, & Anderson, 2006).

Zeng et al. (2011) explored the impact of survivorship among Chinese cervical cancer survivors. Findings from the study revealed that the women were depressed and afraid of cancer recurrence and had a low self-esteem. The researchers found that the survivors suffered rejection which negatively affected their emotional well-being. Other studies cited depression, anxiety and fear as negatively affecting the psychological well-being of cervical cancer survivors (Ashing-Giwa et al., 2004; Frumovitz et al., 2005; Kamau, Osoti, & Njuguna, 2007; Zeng et al., 2011). Similarly, in a cross-sectional study among cervical cancer patients in China, some 52.2% prevalence rate of anxiety and depression was reported. The researchers posited that anxiety and depression co-exist among cervical cancer survivors (Yang, Lui, Wang, Wang, & Wang, 2014). In a related study Syse and Kravdal (2007) noted that vaginal bleeding triggered anxiety among cervical cancer survivors.

Communication has increasingly been considered an extremely important factor in helping people cope with cancer. For instance, Perry and Burgess (2003) describe communication as one of the most important aspects of nursing care of cancer patients, yet it is frequently documented as being poorly handled (McCaughan & Parahoo, 2000). Surveys of cancer patients have repeatedly shown that patients place particular importance on good face-to-face communication with the health professionals responsible for their care (Perry & Burgess, 2003). It is well documented that people within the general population suffer psychological trauma, anxiety and depression on receiving a cancer diagnosis. Perry and Burgess (2003) highlight that those with a cancer diagnosis are three times more likely to suffer from anxiety and depression than the general population; and also have an increased risk of long-term psychological distress. An investigation of the informational needs of 185 women with gynaecological cancer was done in Canada. The authors identified that the most essential information needs of these women focused on information about their disease, treatment availability, side effects of the treatment and prognosis of the disease (Papadakos et al., 2012).

Clemmens, Knalf, Lev and McCorle (2008) described the QoL of 19 long-term cervical cancer survivors in North-eastern United States. Most of the participants disclosed that they did not receive information about cervical cancer and its treatment sequelae. In a related study in the USA, most cancer patients lacked information about their cancer condition, tests and medications (Nedjat-Haiem, Lorenz, Ell, Hamilton, & Palinkas, 2012).

The provision of information to patients is one of the most important factors of supportive cancer care across the whole cancer continuum (Husson, Mols, & van de Poll-Franse, 2011). The goal of providing information is to prepare patients for their treatment, increase adherence to therapy, increase their abilities to cope with the illness and promote recovery (van der Meulen, Jasen, van Dulmen, Bensing, & van Weert, 2008). However, the results of a systematic review shows that about 6–93% of the cancer patients report adequate information provision as an unmet need throughout their cancer experience (Harrison, 2009).

Patients frequently report barriers to receiving the information needed (Jenkins, Fallowfield, & Saul, 2001). Health care providers are often reluctant to give the full context of information about cancer and its treatment, while the majority of cancer patients want as much information as possible about their disease, treatment and rehabilitation (Jenkins et al., 2001). Providing information that is congruent with patients' needs is an important determinant for patient satisfaction and might affect health-related quality of life (HRQoL), anxiety and depression levels of cancer patients. A lack of information, or information of low quality, can lead to depression, anxiety or a decreased mental and/or global HRQoL (Husson et al., 2011). For example, findings from the study of Husson et al. (2011) show that cancer patients with fulfilled information needs and fewer barriers to general information experience less anxiety and depression (Husson et al., 2011). Existing research clearly demonstrates that lack of information is a source of anxiety and depression (D'Souza, Blouin, Zeitouni, Muller, & Allison, 2013). Based on this, some researchers suggested that it is important for healthcare professionals to provide adequate information to patients and families as this can go a long way to reduce anxiety and fear (Beaver & Witham, 2007; Gysels, Richardson, & Higginson, 2004).

A number of studies have cited patients' lack of knowledge related to associated signs and symptoms of cervical cancer (Langley & Mary, 2012; Van Schalkwyk et al., 2008). For example, Langley and Mary (2012) indicated in their study, that the majority of respondents (48% (n=57) did not know what caused the symptoms they experienced. Van

Schalkwyk et al. (2008), and Issah, Maree and Mwinituo (2011) also found in their studies among cervical cancer survivors, that all the participants could not link the signs and symptoms to cervical cancer. Similarly, Durowade et al. (2013) reported in their cross-sectional study that respondents demonstrated poor knowledge of cervical cancer. Further, some studies have also reported inadequate knowledge of cervical cancer among health workers (Mwaka, Wabinga, & Mayanja- Kizza, 2013; Urasa & Darj, 2011;Van Schalkwyk et al., 2008). For instance, Mwaka et al. (2013) revealed that healthcare professionals in lower level health facilities in Uganda do not have adequate knowledge. They were reported to have lacked up-to-date knowledge of cervical cancer. Urasa and Darj (2011) conducted a descriptive cross sectional study among 137 nurses and reported that less than half of the nurses had adequate knowledge regarding cervical cancer. Contrary to earlier views, other studies however reported adequate knowledge of health workers on cervical cancer (Oche, Kaoje, Gana, & Ango, 2013; Tchounga et al., 2014). In view of this, Shah and associates suggested in their study that health workers' knowledge on cervical cancer should be improved (Shah, Vyas, Singh, & Shrivastava, 2012).

Delays in the healthcare setting in the rendering of care to patients with cervical cancers have been reported by some studies and these delays were in the form of late diagnosis and in the referral process (Eze et al., 2013; Maree et al., 2014; Mwaka et al., 2013; Van Schalkwyk et al., 2008). For instance, in the study of Mwaka et al. (2013), participants stated delays in decisions, diagnoses and providing appropriate services, and the subsequent poor treatment outcome. In the same study, there were reports of delay in getting cytology/histology results, and losses of biopsy samples. The participants further stated that these occurrences lead to frustration for the women and their families resulting in distress. The participants in the Mwaka et al. (2013) study in Uganda mentioned that there were few specialized cancer treatment facilities in the countryside which meant that the patients had to travel long distances to the capital to seek treatment. This further compounds the problem of delay.

Van Schalkwyk et al. (2008) found that women experiencing signs of cervical cancer were failed by the public health system as they repeatedly consulted at primary healthcare clinics before they were diagnosed. Participants in the study of Maree et al. (2014) registered their displeasure in the delay of their diagnosis as the participants felt that the action could have contributed to the advanced nature of their conditions.

Misdiagnosis as a healthcare system factor in the diagnosis and treatment continuum has been reported among cervical cancer survivors by some studies (Mwaka et al., 2013; Van Schalkwyk et al., 2008). In their study, Wainer et al. (2012) observed that some of gynaecological cancer survivors were misdiagnosed which delayed treatment.

2.3.2 Fear of Death

Akyuz et al. (2008) also mentioned that patients with gynaecologic cancers suffer psychological symptoms, including fear of death. Specifically, in their study of Latina patients with cervical cancer, the researchers reported that the women had emotional challenges as they entertained the fear of death and the worsening of their disease condition (Ashing-Giwa et al., 2006). Mabena and Moodley (2012) also reported fear of death among cervical cancer patients in their study. They argued that patients’ fear of death was directly related to their disease progression. In the study by Vilhauer (2008), most of the participants mentioned periodic obsession with the fear of death. The fear of death became intense when the cancer progresses or when the sufferers become aware of the death of other people with the same disease. The fear of death becomes more intense when the women view images of themselves in other sick patients (Vilhauer, 2008). It has been reported that the cancer experience resulted in participants realizing their own mortality. For instance, in the study of Holt and colleagues, the authors reported that the participants feared death and had thoughts of the welfare of their children after their death (Holt et al., 2009).

2.3.3 Suicide Tendencies

Cancer diagnosis and treatment causes tremendous physical and psychological burden (Shime & Halm, 2011) which may lead to suicide. Therefore, the risk of suicidal ideations in cancer patients is higher and twice that of the general population (Misono, Weiss, Fann, Redman, & Yueh, 2008; Walker et al., 2008). For example, Walker et al. (2008) in their study indicated that the risk of suicidal thoughts among the cancer population was noted to be three times higher than the general public. Furthermore, they stated that 7.8% of the patients had thoughts of suicide or self-harm (Walker et al., 2008). Other researchers also supported this claim. They reported a prevalence rate of 17.7% of suicidal ideations in a population based sample of cancer patients (Schneider & Shenassa, 2008). Other studies have also estimated that about 8.5-26% of terminal patients have high levels of desire to hasten death (Mystakidou, Parpa, Katsouda, Galanos, & Vlahos, 2006; Shime & Hahm, 2011).

According to Jones, Huggins, Rydall and Rodin (2003) and Mystakidou et al. (2006), the desire to commit suicide among cancer patients has been linked to a number of factors: low physical functioning; perceived lack of social support; single status; and pain. These factors have often been mentioned as being consistently correlated to the desire for a death (Mystakidou et al., 2006; O'Mahony et al., 2005; Shime & Hahm, 2011). Some researchers reported that uncontrolled pain is a contributing factor to suicidal tendencies among cancer survivors (Nuhu et al., 2008; Recklitis, Lockwood, Rothwell, & Diller, 2006). Psychosocial factors such as anxiety and depression also have an impact on the desire to hasten death (Shime & Hahm, 2011). Additionally, dependency, a sense of burdening others, meaninglessness and quality of life were reported to be associated with suicidal tendencies among the cancer population (Morita, Sakaguchi, Hirai, Tsuneto, & Shima, 2004; Shime & Hahm, 2011).

Suicide has been identified as a significant public health problem among women diagnosed with gynaecologic malignancies. For instance, Ward, Roncancio and Plaxe (2013) posit that suicide is a frequent cause of death among women with gynaecological cancers. Ward et al. (2013) hold the view that women with gynaecologic cancer report poor body image, thus, the combination of emotional and psychological stressors increases the risk of suicide among women with gynaecologic cancers. The authors suggested that it is important to screen gynaecologic cancer patients for psychological distress and risk of suicide given that the risk of suicide among gynaecologic cancer patients is greatest. Mahdi et al. (2011) agree that gynaecologic cancer patients have a higher risk of suicide than the general population. They stated that survivors of gynaecologic malignancies often experience feelings of depression, burdensomeness and social isolation and reduced sexual function. These collectively increase suicide risks (Mahdi et al., 2011).

2.3.4 Cognition/Attention and Distress of Diagnosis

According to Nedjat-Haiem et al. (2012), participants in their study seek help at the time their cancer symptoms worsened. Regarding immediate reactions to patients' diagnosis, Nedjat-Haiem et al. (2012) observed in their study that all participants expressed shock; and disbelieved fear were their initial reaction to their advanced cancer diagnoses. In other studies such as Holt et al. (2009), it was noted that participants showed anger and denial upon hearing their cancer diagnosis. The participants in the study further reported that they never thought they could have cancer. Lynos and Shelton (2004) also reported that some women with cervical cancer were embarrassed and ashamed of their diagnosis whilst others experienced fear and anxiety related to their diagnosis and treatment.

In summary, the reviewed literature indicated that the psychological well-being of women with cervical cancer in entirety is poor.

2.4 Social Well-being of Women with Cervical Cancer

The review of literature on the social well-being of women with cervical cancer was limited to affection/ sexual concerns and impaired relationships; changing roles, responsibilities and family distress; social isolation; support networks; and economic impact.

2.4.1 Affection/Sexual Concerns and Impaired Relationships

According to Tierney (2008), gynaecological cancer diagnosis and its treatments have the ability to directly affect one or more of the sexual response phases (desire, arousal/ excitement and orgasm) which may lead to sexual dysfunction. Numerous studies have reported on difficulties women have with sexual desire/arousal (Amsterdam & Krychman, 2006; Burns et al., 2007; Liavaag et al., 2008; Tornatta et al., 2009); lubrication (Liavaage et al., 2008; Tornatta et al., 2009); and orgasm (Amsterdam & Krychman, 2006; Tangjitgamol et al., 2007).

Carter et al. (2005) in their cross-sectional study revealed that women who have undergone treatment for gynaecologic cancer and have lost their fertility, expressed pain during vaginal penetration (62%); low levels of sexual desire (56%); and dissatisfactions with their overall sex lives (67%). Other studies involving patients with gynaecological cancers have also identified that patients on treatment for gynaecological cancers experienced sexual dysfunction after diagnosis and treatment (Carter et al., 2005; Gotay, Farley, Kawamoto, & Mearig, 2008; Greenwald & McCorle, 2008; Lindau, Gavrilova, & Anderson, 2007; Matulonis et al., 2008; Tangjitgamol et al., 2007). Related studies have also revealed that the diagnosis and treatment of gynaecological cancers among women have resulted in the reduction of sexual functioning (Liavaag et al., 2008; Van de Klundert, Incrocci, Hullu, & Snijders-Keilholz, 2007; Wenzel et al., 2005). In the study of Bergamark, Avall-Lundqvist, Dickman, Henningsohn and Steineck (2002), sexual dysfunction has been rated as the most disturbing symptom out of a total of 22 symptoms by women following the diagnosis and treatment of cervical cancer.

A study has shown that irradiated cervical cancer survivors experience much greater sexual dysfunction than those treated with surgery and chemotherapy (Frumovitz et al., 2005). Krikeli et al. (2011) in their study in Greece emphasised the impact of radiotherapy and radio-chemotherapy on the QoL of cervical cancer survivors. Their findings indicate that survivors who received only radiotherapy had more physical impairments such as tightening of the vagina, poor sexual functioning and decreased QoL than survivors who received chemo-radiation. Specifically, the pain, profuse offensive vaginal discharge and bleeding as well as other vaginal changes such as vaginal dryness, and atrophy associated with cancer and treatment were identified as factors that affected the sexual lives of women with cervical cancer (Bukovick et al., 2008; Cleary & Hegarty, 2011; Lammerink et al., 2012). Due to the vaginal alterations and loss of libido, the women shy away from sex (Herzog & Wright, 2007; Maree et al., 2013; Stead et al., 2007)

The study by Stafford and Judd (2011) to determine the challenges of QoL in women with gynaecologic cancer in Australia, showed that 68% of participants had no interest in sex and about two-thirds of older participants and women without partners were not sexually active. Kamau et al. (2007) identified that the majority of survivors with cervical cancer receiving radiotherapy lacked interest in sexual intercourse. However, the researchers indicated that a few of the survivors above 50 years reported interest in sexual activities. Similarly, in a cross-sectional correlation study in Brazil to evaluate the quality of life of 149 women with cervical cancer, Fernandes and Kimura (2010) identified that most cervical cancer survivors, even though they were living with their spouses, were not involved in sexual activities. These survivors reported lack of interest in sexual activities and added they paid very little or no attention to sexual activity. In addition, these researchers claimed the survivors also testified to fear of engaging in sex, feeling less sexually attractive, and having a narrow or shortened vagina. These symptoms were noted to have the highest negative evaluation. The researchers also noted that being married improved the emotional well-being of survivors of cervical cancer.

Results from a quantitative longitudinal study which assessed the sexual functioning and vaginal changes among (n=118) cervical cancer survivors revealed that sexual dysfunction was reported by women up to 2 years post completion of radiotherapy. In terms of sexual desire, about 60.9% reported a deterioration in sexual interest and 62.5% reported a decrease in vaginal lubrication at 12 months post treatment. A key finding in that study was that about 45% of women were never able, or only occasionally able, to complete sexual intercourse (Jensen et al., 2003). In a related study, it was noted that many cervical cancer survivors in China delay in the resumption of sexual activities because of not having a partner, being too tired to have sex, fear that the sexual activity will render the cancer treatment ineffective, and husbands not initiating sexual activity because of fear of the disease (Zeng et al., 2011).

Additionally, fears about injuring or aggravating the affected area adversely affected the frequency and quality of sexual relations among cervical cancer survivors (Ashing-Giwa et al., 2004). However, for those who resumed sexual activity in that study, the act was infrequent because of vaginal dryness, dyspareunia and worry about the disease (Zeng et al., 2011).

Survivors of gynaecological cancers have significant problems maintaining their sexual functions because of fear of their husbands semen making the condition worse and the possibility of transmitting the condition to their male partners (Griemel et al., 2009;

Hsu et al., 2009; Reis et al., 2010) . Some women with altered body image mentioned that their lack of interest in sexual activities with their spouses was because they feel sexually unattractive (Cleary et al., 2011; Matulonis et al., 2008; Rasmussen et al., 2008; Sacerdoti, Lagana, & Koopman, 2010). However, a few cervical cancer survivors embrace sex willingly because of psychological stability, the need to feel feminine and to maintain their relationships (Afiyanti & Milanti, 2013; Khoo, 2009; Maree et al., 2013; Stead et al., 2007). In some instances, women are pressured by their partners to engage in sexual activity even though they were tired and sick (Nelms & Goski, 2006; O'Sullivan et al., 2006).

Wenzel et al., (2005) described the QoL of 51 cervical cancer survivors and reported that 16 of the women were not sexually active. Reasons cited by the women included no partner, no interest and/or had a partner who was not interested, fatigue, physical problems and pain with penetration. In effect, the women had poor sexual functioning. The researcher further stated that at the time of diagnosis, 39 of the cervical cancer survivors were married, 29 of which remained married at the time of the interview. However, nine of the survivors were divorced; of these, four women stated that their divorce or separation occurred after their diagnosis therefore attributed their divorce to cervical cancer. Similarly, Syse and Kravdal (2007) reported an increased divorce rate among women with cervical cancer.

Shell, Carolan, Ying Zhang and Meneses (2008) suggest that difficulties in relationships are likely to arise following cancer and its treatment when couples fail to communicate feelings and do not share the need for intimacy. They claimed that there is a direct relationship between sexual activity and intimacy. It follows that when sexual activity decreases so does the intimacy within a relationship (Hughes, 2000). It has been reported in the study by De Groot et al. (2007) that the lack of communication and intimacy has the tendency of causing strain and dissatisfaction within relationships that adds to the entire burden of gynaecological cancer for women.

Issues concerning separation and divorce seem to be real in the lives of some women who have advanced cervical cancer whether they are married or single. Cervical cancer and its treatment, according to Zeng at al. (2011), had a negative effect on the marital relationship of survivors. Hacaoglu and colleagues established that relationships of couples who had problems before diagnosis of the disease gradually worsened during the course of the disease and the treatment. The investigators observed that marriages that were already steady before the cancer diagnosis improved over the course of the coping with the disease. Furthermore, it was noted that a good marital relationship was instrumental for coping emotionally with the disease and its effects (Hacaoglu, Kandemir, & Civil, 2007).

The loss of regular sex in relationships between cervical cancer survivors and their partners in some instances ignited anger leading to separation, divorce and other forms of rational difficulties (Afiyanti & Milanti, 2013; Ashing-Giwa et al., 2004; Baze et al., 2008; Lin et al., 2011; Zeng et al., 2011). In South Africa, a study showed that partners of the women with cervical cancer told them to separate until they seek treatment. Some of the men sought sexual pleasure with other women while a few of the survivors willingly asked their partners to find other women since they were not in the position to satisfy their sexual needs (Maree et al., 2013). Similarly, Indonesian cervical cancer survivors also asked their spouses to find other women as they could not satisfy their sexual desires (Afiyanti & Milanti, 2013). Likewise, unmarried women’s relationships with their boyfriends ended as a result of suffering from cervical cancer (Lin et al., 2011).

Some single cervical cancer survivors experienced loss of libido in part due to pain and fear that sex would worsen their condition. On the other hand, survivors who were married reported forcing themselves to have sex with their husbands. Other survivors did not feel their relationship was adversely affected. Other studies reported reduction in the interest and frequency of sexual activity among gynaecological cancer survivors (Liavaage et al., 2008; Lindau et al., 2007) and more precisely, among cervical cancer survivors (Burns et al., 2007; Griemel et al., 2009).

Survivors of gynaecological cancers stated that their cancer experience had a negative impact on how they felt as women. This feeling was found to be common among survivors of child bearing age who linked femininity with the ability to bear children (Jensen et al., 2004) and this resulted in emotional distress over the loss of fertility (Baze et al., 2008; Reis et al., 2010; Sacerdoti et al., 2010).

2.4.2 Changing Roles, Responsibilities and Family Distress

Studies have shown that almost all patients with advanced cervical and gynaecological cancers experience changes in their daily roles and responsibilities (Akyuz et al., 2008; Zeng et al., 2011). It has been reported that household roles and responsibilities are taken over by patients’ parents, husbands, children and other family members while they receive treatment (Akyuz et al., 2008; Zeng et al., 2011). For instance, in the study of Zeng et al. (2011), a majority of the cervical cancer survivors disclosed that their household roles/chores and responsibilities were taken up by their husbands and parents. This made the women dependent and unable to carry out the duties they were performing hitherto their diagnosis and treatment. According to (Lindahl-Jacobsen, Hansen, la Cour, & Sondergaard, 2014), many cancer patients have problems performing activities of daily living (ADL). The authors argued that cancer patients experience physical, psychological and social problems during and after cancer treatment, including difficulties with ADL. In that study, it was observed that patients with persistent cancer disease tend to have more problems with ADL compared to cancer-free controls.

Kamau et al. (2007) in their study found that the quality of life of the physical and functional domains was negatively affected. For instance, participants reported feeling tired and weak; however, the cervical cancer survivors neither needed assistance with daily activities nor spent time in bed. A study in Poland also revealed that women with cervical cancer experienced fatigue, tiredness and difficulty in performing activities of daily living after radiotherapy (Pasek et al., 2012). Furthermore, Lynos and Shelton (2004) in their study reported that participants diagnosed with cervical cancers and treated with radiotherapy had fatigue but could perform their daily activities. In addition, a number of studies maintained that cancer patients are less active as a result of the cancer related pain experience. The severity of the pain inhibited their involvement in daily activities such as lifting and dragging of loads (Doumit, El Saghir, Huijer, Kelley, & Nassar, 2010; Vilhauer, 2008).

The diagnosis of a woman with gynaecological affects not only the survivor but the family in various ways (Hodgkinson et al., 2007; Lowdermilk & Germino, 2000). For instance, Akyuz et al. (2008) in their study of women with gynaecological cancers and their male partners in Turkey noted that about half of the partners reported they had experienced some physical and emotional difficulties such as fear, anxiety, stress, fatigue, and insomnia during this period. Furthermore, they reported that the thoughts of being a burden to the family made the women think that they have placed emotional burden on their husbands. The participants in the study also disclosed that the financial burden their cancer diagnosis and treatment had placed on the entire family brought undue distress on the family. In view of this, the husbands and children of the women have expressed their fears that their wives/mothers would die of the disease. Other studies have shown that gynaecologic cancer not only creates problems for the cancer patients, but can extensively affect the immediate family because women play a central role in the management of the family in daily life. In times when women undergo intensive treatment, most of the cancer patients’ roles are taken over by other family members including their partners, adult children, and relatives.

It has been reported that people caring for cancer patients can experience helplessness, uncertainty, stress-related agitation, depression, and fear of loneliness. Kennedy and Lloyd-Williams (2009) in their study explored how children cope when their parents are diagnosed with advanced cancer in the UK. Children were reported to have been distressed at receiving the news of their parents’ diagnosis. The side effects of the treatments and hospital visits also increased the distress in the children. The children found it difficult seeing their parents ill or suffering as a result of cancer and this made them worried. Social activities and responsibilities were the aspects of the children’s lives that were most impacted upon by a parent’s cancer diagnosis. The investigators concluded that children are largely affected by a parent’s cancer diagnosis of advanced cancer.

2.4.3 Social Isolation in Cervical Cancer

Isolation in the life of a woman with cervical cancer may stem from different sources. The physical presentations of the disease such as offensive vaginal bleeding and discharges may cause some women to be isolated. Findings from Van Schalkwyk et al. (2008) and Maree et al. (2013) support the assertion that offensive vaginal discharges and bleeding may cause isolation. Some survivors felt isolated within the community in which they lived because nobody visited them at their homes. In the same study survivors stated that they could not attend church because it was against their religious faith for a bleeding woman to enter the chapel (Van Schalkwyk et al., 2008).

In another study, a cervical cancer survivor stated that she was compelled to send her grandchildren elsewhere so she can take care of the smelling room by opening the door and windows, and also to wash her clothes that are soaked with offensive discharges which she could not have done in the presence of the grandchildren (Maree et al., 2013). The implication is that she gets the opportunity to stay alone. Similarly, Cavin-Wainscott (2013) noted that extreme haemorrhaging (excessive bleeding) from the vagina is common as is foul-smelling discharges which leads to social isolation and despair. Moreover, some women are isolated as a result of the loss of fertility as a side effect of their treatment. Reis et al. (2010), in their findings reported that participants who lost their fertility due to cancer treatment, felt marked and isolated from other fertile women. According to Zeng et al. (2011), changes in daily lives and feeling of social isolation were reported. More than half of the participants perceived that cervical cancer had a negative impact on their social functioning, limited social network and feeling of isolation (Zeng et al., 2011). Other researchers acknowledged that effects of gynaecological cancer on social life of the women and their partners varied according to the stage of the cancer, post-treatment duration, the person’s characteristics, and social environment. The investigators further mentioned that patients with more advanced cancer and those whose treatment took 6 months to a year had a significant decrease in social life and relationships (Akyuz et al., 2008)

Participants in the study by Schmid-Buchi, Halfens, Dassen and van den Borne (2011) reported the feeling of impairment in their physical and leisure activities. Additionally, the participants were concerned about their body image. They reported feeling less feminine and attractive, complained of weight gain, changes of body perception, and appearance (Schmid-Buchi et al., 2011). Hair loss was cited in some studies as a side effect of cancer treatment. The researchers indicated that survivors in those studies felt stigmatized as a result of altered body appearance. Survivors experienced poor social interactions (Chon, Champion, Geddes, & Rashid, 2012; Hanson, 2007; Rosman, 2004). This explains that visible body disfigurements as side effects from cancer treatment prevented survivors from social interactions which made survivors maladjusted socially (Arunchalam, Thirumorthy, Devi, & Thennarasu, 2011).

It is further reported that CCS expressed more negative feelings about their bodies after surgery (abdominal scars, adverse effect on self-image and self-worth as women); and these deep concerns had an impact on their relationships (Ashing-Giwa et al., 2004). It was stated that the survivors feel avoided when they meet other people. Some survivors felt they were being watched in specific ways, or even greeted with specific compliments. Therefore, body changes do not only denote the physical sign of cancer but also represents the social presence and representation of cancer (Rasmussen, Hansen, & Elverdam, 2010).

2.4.4 Support Networks of Women with Cervical Cancer

Shiozaki et al. (2011) considers support to be a protective influence therefore individuals who receive various forms of support are more likely than not to maintain a healthier state even in the face of life-threatening events such as cancer.

Koffman, Morgan, Edmonds, Speck and Higginson (2012) explored social support networks and their meaning among black Caribbean and white British patients living with advanced cancer. The findings suggested that the presence of a spouse or partner was an essential feature within social support networks. Additionally, participants mentioned close family friends and neighbours, friends, and extended family members as other sources of their social support connectedness. Support from their spouse or partner was phenomenal in their lives as their feebleness increased as a result of their advanced cancer status.

Maree et al. (2013) explored the experiences of life partner support among hospitalized women receiving treatment for cervical cancer in South Africa. Their findings indicated that the support received from the participants’ partners varied. For instance, some of the women received domestic and financial support from their partners while others did not receive any form of support.

Similarly, Ashing-Giwa et al. (2004) reported that women in their study mentioned support from immediate and extended family members, mothers, spouses/partners and children; in that the family members accompanied the cervical cancer survivors to appointments, helped in medical compliance and transportation as well as performed household chores. The investigators further noted that the desire of the cervical cancer survivors to see their children grow up served as a motivation to get well. Maree et al. (2013) equally observed that life partners/spouses accompanied cervical cancer participants to follow-up consultations.

Various sources of social support have been reported by women with cervical cancer. For instance, husbands, neighbours, church members and employers have been reported to provide enormous social support for women with cervical cancer (Van Schalkwyk et al., 2008). Maree et al. (2013), in their study, stated that almost all the women depended on their partners for financial support; this motivated some of the women to cope better with the disease. In that same study, regular communication between women and their partners was seen as a source of support; and hence, helped women to cope better with their condition. Similarly, Awasthi and Mishra (2013) in their study among cervical cancer survivors reported that social support was associated with less disease consequences such as pain. They further established that the existence of components of social supports such as emotional, informational, and social companionship culminating into a strong social support enabled the survivors to adjust physically and psychologically to the cancer experience. Cervical cancer and its treatment have been reported to affect the social and emotional well-being of women with the disease (Zeng et al., 2011). Social support was established by Guo, Sheng, Lui and Hua (2004) and Zeng et al. (2011) to have a positive influence on social well-being of women with cervical cancer and social support was mostly from family and friends (Kamau et al., 2007; Zeng et al., 2011). In the study of Kamau et al. (2007), the majority of the women with cervical cancer receiving radiotherapy in Kenya received social support from their families and friends and took part in leisure activities. On the contrary, Wenzel et al. (2005) emphasized in their study that survivors who did not have ample social support were distressed.

Generally, cervical cancer survivors in a study (Ashing-Giwa et al., 2004) expressed satisfaction with the support received from doctors as well as their relationships with doctors. The survivors noted that the relationship was very good as the doctors cared for them, making them feel comfortable. Although some CCS felt their doctors were affable, they were dissatisfied with their insufficient explanation of test results. In addition to that, CCS also expressed a number of concerns including the long wait for appointments.

Ashing-Giwa et al. (2004) also reported in their study that CCS had concerns about lack of finances, particularly feeling ashamed if they had to ask for financial assistance. Even though all the women in that study agreed that family support was essential to emotional well-being and treatment adherence, unfortunately some survivors stated that they did not receive adequate family support.

2.4.5 Work Related Issues among Cervical Cancer Survivors

Zeng at al. (2011) stated that cervical cancer and its treatment had a negative effect on the employment status of survivors. Cancer diagnosis and its treatment have been noted to disrupt the working patterns of patients (Kennedy et al., 2007). Cervical cancer, with its associated signs and symptoms as well as the treatment consequences, may affect the working life of sufferers. Due to the physical presentation of the disease and its treatment, most of the women who were initially in a form of employment may have problem with their working lives after their diagnoses. From the findings of Van Schalkwyk et al.

(2008), the profuse vaginal bleeding, offensive vaginal discharges, and severe pain as part of the disease process compelled the women to stay away from work.

Employment is key in the life of an individual as it provides financial security, improves health, social interactions and sense of contribution (Nilsson, Olsson, Wennman-Larsen, Petersson, & Alexanderson, 2011). Again, work has been shown to have an essential impact on quality of life and most women diagnosed with cancer considered work as a normalizing factor (Kennedy et al., 2007; Rasmussen & Elverdam 2008).

Reports from a numbers of studies from Europe and America reported that poor health may hinder cancer patients' ability to work. Similarly, poor health can lead patients to experience restrictions and a range of difficulties relating to work (Bednarek & Bradley, 2005; Bouknight, Bradley, & Luo, 2006; Short, Vasey, & BeLue, 2008). Challenges may arise in the working life of people suffering from cancer because of lack of support from co-workers and managers as well as the physical and cognitive demands of work (Hoffman, 2005; Taskila & Lindbohm, 2007). A number of studies reported that positive workplace support from managers and colleagues play a vital role in the lives of cancer survivors. It was noted that this support was useful to the women as it helped them financially and socially (Kennedy et al., 2007; Main, Nowels, Cavender, Etschmaier, & Steiner, 2005; Nachreiner et al., 2007). Cancer survivors in UK reported that work place support from supervisors and co-workers has a positive impact on their lives (Amir, Neary, & Luker, 2008).

In the United Kingdom, cancer survivors were reported to have stopped work temporarily largely because of their cancer conditions (Kennedy et al., 2007). In the same piece, women who felt they needed to work had to reduce the number of hours they work, which obviously affected their income as less hours of work pays less. Similar views were reported in a systematic review in Germany. In that review, it was reported that a high proportion of cancer survivors experienced momentary changes in work schedules, work hours, wages and a decrease in work ability compared to the non-cancer group (Mehnert, 2011).

Ashing-Giwa et al. (2004) reported that cervical cancer survivors were uncomfortable disclosing their cervical cancer diagnosis to co-workers/supervisors. They were concerned about being unable to perform the duties required of their job, and feared losing their jobs and being unable to provide for their families. In view of this, some survivors did not disclose the illness to their supervisors; most did not believe that their employers would be supportive. However, it was reported that some of the cervical cancer survivors disclosed their diagnosis to their supervisors. Of those who did, none reported receiving support. Conversely, several indicated that disclosing the illness to co-workers was helpful. In an instance, a CCS reported that she was forced to retire early. Others reported having to reduce work during surgery and the recovery period. Some survivors also felt that co-workers treated them as if they were now more fragile and limited in their abilities. Overall, none of the women reported having been discriminated against as a result of their illness. Similarly, Ashing-Giwa et al. (2006) reported that in advanced stages of cervical cancer with poor prognosis and loss of employment as a result of treatment and effects of treatment led to financial challenges which affect the QoL of the women. Klee, Thranov and Machin (2000) reported in their study of 118 patients with cervical cancer that one third of all working patients suspended working for 6–24 months after the diagnosis. This is likely to negatively affect their finances.

2.4.6 Economic Impact of Cervical Cancer

The cost of treatment of cervical cancer is relatively high and patients who strive to seek treatment will have to be financially sound (Sharp et al., 2013; Wainer et al., 2012). In some developed countries, provision has been made for insurance cover that may be private or instituted by the state (Sharp et al., 2013; Stafford & Judd, 2010). In their retrospective cohort analysis, Levinson, Bristow, Donohue, Kanarek and Trimble (2011) attempted to determine the impact of payer status on the likelihood of receiving treatment for invasive cervical cancer. It was found that the insurance status of patients largely determines the type of treatment the patient received. Patients who were insured had financial assistance to some extent; even with the insurance those who paid more, received better treatments (Levinson et al., 2012). The entire cost involved in treatment of cervical cancer goes beyond just the physical cost of any of the treatment modalities.

A study in Australia considered other factors that may add to the entire cost of treating cancer. The authors indicated that rural women who had to travel to treatment centres were noted to have incurred a lot of cost. The cost of transportation, accommodation, feeding, treatment of other health problems that may surface and time lost from work by the patient herself and in some cases the partners all added to high treatment cost (Wainer et al., 2012).

In line with the cost of treatment of cervical cancer, a study in South Africa indicated that some women received financial support from their husbands; others took grants from family members while some were supported by their siblings (Maree et al., 2013). Cost of treatment of cancer is enormous both for the patient and family as a whole (Levinson et al., 2012; Maree et al., 2013; Wainer et al., 2012). In a related study in Tanzania, poor social support was reported among study participants. The participants stated financial problems as their highest challenge (Masika et al., 2012). The study suggested that these needs must be met to enhance the QoL of cancer patients.

Kamau et al. (2007) conducted a study amongst women with cervical cancer receiving radiotherapy in Kenya to determine the effect of diagnosis and treatment of cervical cancer on QoL. The study found that most participants (53%) had poor QoL.

Some of the key factors which negatively affected QoL were financial constraints and reduced income generation. Similarly, the QoL of Polish women with cervical cancer was evaluated and it was revealed that financial burden worsened the QoL of the women (Pasek et al., 2012). Krikeli et al. (2011) found in their study that financial constraint was a major problem for cervical cancer survivors who received chemo-radiation in Greece. To this end, Nedjat-Haiem et al. (2012) observed that participants in their study suffered some financial burden associated with their cancer experience. It was noted that financial hardship stemmed from frequent hospital attendance and loss of job. According to Lynos and Shelton (2004), about 57 (95%) of women studied who were receiving treatment for cervical cancer had financial constraints and found it difficult paying for the cost of their treatment. However, none of the women received financial support from their employer.

In summary, the various literatures indicate that survivors enjoyed great social support. However, the survivors encountered relational problems, financial concerns, and social isolation that may negatively affect the social well-being of survivors.

2.5 Spiritual Well-being of Women with Cervical Cancer

In this study, the review on spiritual well-being focused on the spirituality and religiosity meaning of illness, hope and coping strategies of women with cervical cancer.

2.5.1 Spirituality and Religiosity

Spirituality and religion can be useful resources for individuals and the families of individuals faced with cancer. Such individuals turn to a higher power or religion as a way of coping (Nedjat-Haiem et al., 2012; Thune-Boyle, Stygall, Keshtgar, & Newman, 2006). Religiosity is reported to aid with cancer coping and the literature indicates religious concerns are important to health and quality of life among cancer patients (Laubmeier, Zakowski, & Bair, 2004). Church attendance has been considered a way of coping among cancer patients (Thune-Boyle et al., 2011).

Coping strategies adopted by cancer survivors are thought to play an important role in managing the physical and psychosocial effects associated with a cancer diagnosis and treatment (Costanzo et al., 2006). In essence, effective coping may bring about positive QoL outcomes, and ineffective coping mechanisms may lead to poor QoL outcomes among cervical cancer survivors.

A study in the USA found that congregational activities, church membership, frequency of church and reading of religious materials, watching religious television programmes and increased praying was mostly used by the cancer survivors (Hamilton, Agarwal, & Carter, 2011; Lauver et al., 2007; Walter, 2010). In addition, spirituality can avert cancer patients from falling into desperation (McClain, Rosenfeld, & Breitbart, 2003). A belief in God and religion were considered important factors for coping with the diagnosis of cancer (Doumit, Huijer, & Kelley, 2007; Holt et al., 2009). In Turkey, survivors of gynaecological cancers use worship and prayer as coping mechanisms (Akyuz et al., 2007, 2008). In the studies of Ashing-Giwa and colleagues, cervical cancer survivors accepted prayer and seeking God’s guidance and assistance in coping with the illness. They further mentioned that the participants in their study view doctors as instruments of God in healing. Faith was a significant means of coping with cervical cancer and its pain. In the same study, participants were said to have found support and relief through church and religious faith. Likewise, they experienced peace in prayers. Furthermore, some of the respondents held the view that the condition is beyond their personal control and therefore in God’s hands. This notion made them feel at peace by turning their circumstances to God and accepting God’s will. It is noteworthy that participants received support from clergy as they move along the trajectory of cervical cancer (Ashing-Giwa et al., 2004, 2006). Cancer patients adopt faith in God, acceptance, will power, seeking for information, and social support as coping strategies adopted in their cancer experience (Awasthi & Mishra, 2013; Doumit et al., 2007, 2010; Mabena & Moodley, 2012).

2.5.2 Meaning of illness among Women with Cervical Cancer

In finding meaning to their disease, cervical cancer survivors in the study by Zeng et al. (2011) made varying deductions. Some of the women perceived positive gains from their cancer experience. The changes included a more positive outlook on life such as cherishing life more; appreciating relationships with others; viewing the cancer experience as a rebirth; the relationship with their husbands becoming more intimate; and their family relationships becoming more harmonious. Other studies have similar thoughts that gynaecological cervical cancer patients perceived a more positive outlook on life, treasuring life more (Akyuz et al., 2008; Clemmens et al., 2002; Hodgkinson et al., 2008). For instance, in the study of Akyuz et al. (2008), the participants stated that they acknowledged an increase in spiritual presence in their lives. Learning that they might die meant that they felt drawn to re-assess their relationship with God and recognise that they needed something more powerful than themselves to see them through their cancer experiences. Additionally, becoming sensitive to others needs is another positive impact that survivors of gynaecological cancer could have (Molassiotis, Chan, Yam, Chan, & Lam, 2002).

According to Holt et al. (2009), the role of having faith and belief in God was viewed as highly important for coping. Participants in the study disclosed an increase in their faith after they were diagnosed of cancer. In addition to that, prayer was seen as important in coping with and recovery from cancer. Prayer was reported to have given strength to the cancer survivors. The participants had the notion that healing can only come from God and not through doctors alone. It was also thought that God allows events to occur for a purpose. It was argued that God provided the cancer disease so as to give the participants a reason to give testimony to others and also to make the participants stronger. Similarly, in studies conducted by Holt et al. (2009), Mabena and Moodley (2012), and Nedjat-Haiem et al. (2012) the participants acknowledged the role of God as a healer, either directly or through doctors and nurses as the participants believed that God gave the nurses and doctors the ability to heal.

Correspondingly, Mabena and Moodley (2012), in their study noted that cervical cancer survivors placed various meanings on their encounter with the illness as they sought spiritual meaning from God. As reported, the participants said the disease came from God, a thought that helped them to cope. The disease was seen as God’s own idea (Mabena & Moodley, 2012). Similar to earlier views found in the studies of Holt et al. (2009), the participants in Mabena and Moodley (2012) study indicated that God permitted the illness in their lives so they can be leaving testimonies to others after receiving healing.

In contrast, some participants attributed the cause of the disease to the devil (Holt et al., 2009), and witchcraft (Mabena & Moodley, 2013). For instance, cervical cancer was reported to have been as a result of a punishment from immoral act in the past or a curse. This made some of the participants disappointed in God (Mabena & Moodley, 2013). In an earlier study in Ghana, it was found that apart from illness being as a result of punishment, the women in the study believed their illness was caused by witchcraft, ghosts or sorcery (Mill, 2001).

Some studies have shown that patients who suffer from gynaecologic cancers found several meanings from their cancer experiences. Zeng et al. (2011) demonstrated that the Chinese survivors of cervical cancer perceived a more positive outlook on life and treasured life more. These results are consistent with those of studies that were conducted in Western countries (Akyuz et al., 2008; Clemmens et al., 2008; Hodgkinson et al., 2007). An additional positive impact that survivors of gynaecologic cancer in Hong Kong identified included being sensitive to others' needs (Molassiotis et al., 2002). Other survivors mentioned giving back to society in a related study as a positive change from experiencing cervical cancer (Ashing-Giwa et al., 2006).

2.5.3 The Will to Live and a Sense of Hope

Holt et al. (2009) in their qualitative study reported that many of the participants believe that individuals could will themselves well. The participants further believed that the mind holds great power so that by holding positive or negative thoughts or speaking positively, a person could influence the prognosis. In that study, the participants coped with their cancer by speaking and thinking positively. In the study by Mabena and Moodley (2012), women with cervical cancer demonstrated their will to live. Participants in that study were reported to have stated that they wanted to live for their children. Other participants viewed their illness as a project that will be rewarded at the end of the entire experience which made the women will themselves to live.

Similarly, spirituality and faith are very essential in maintaining hope as an individual travels along the trajectory of a life threatening illness such as cancer (Esder & May, 2007) and helps to find meaning and ability to return to normal life (Reb, 2007).

Hope has been considered as potent factor in coping (Felder 2004) and quality of life (Esbensen, Osterlind, Roer, & Hallberg, 2004; Ferrell et al., 2005). Having hope of cure was a way of coping adopted by women with gynaecological cancers (Somjai & Chaipoom, 2006). Furthermore, hope could enhance coping and diminish existential distress whenever patients are confronted with mortality and other existential challenges. Hope was reported to help the participant in three ways: to shift perception of death from overwhelming horror towards suppression of peaceful acceptance; to foster reconciliation instead of uncertainty when adapting to a new phase of life; and to establish go-ahead spirit instead of resignation as their identity (Schaufel, Nordrehaug, & Malterud, 2011).

Cervical cancer survivors stated in a study that interacting with other survivors gave them hope in their own circumstances. Again, it was reported that noticing a remission in their earlier presenting symptoms increased the hope of most of the patients (Mabena & Moodley, 2013). The meaning of hope was investigated among newly diagnosed patients with gynaecological cancer. Findings from that study showed that the women had hope of being cured hence prayed to God for healing. Additionally, the researchers reported that the participants saw hope as something that contributed to courage spiritually which was linked to strength and will power as well as faith in God (Hammer, Mogensen, & Hall, 2009).

According to the findings of Nedjat-Haiem et al. (2012), participants stated that survivorship in cancer experience was in the hands of God and therefore, believed that leaving their illness in the hands of God provided a sense of hope and the strength to cope with the illness. The faith the women had in God moved their fear of death to the possibility of survival. Faith in God urged the women to move on in the face of their cancer experiences. Apart from faith and prayer, the researchers cited acceptance, avoidance, distraction and resignation as other coping strategies employed by women coping with their cancers. Specifically, the women stated that acceptance of their condition enabled them to have inner peace to survive their cancer and cope. The women had their worries about their condition diminished as they accepted their condition. Again, acceptance of the cancer condition compelled the women to adhere to their treatment schedules offered by the healthcare providers in order to survive.

Hope was seen as fundamental to life, a will to be alive and to find meaning. Hammer et al. (2009) reported that hope had a relational dimension as it emanated from significant others and love from husbands, children and grandchildren gave the women hope to move on.

It is evident in the literature that women with advanced cervical cancer may have a relatively good spiritual well-being as the women most often than not try to adopt coping strategies to cope with their cancer diagnosis and treatment.

In summary, the literature review revealed that advanced cervical cancer and the treatment modalities employed affect the physical well-being, psychological well-being, social well-being and spiritual well-being of survivors. Most of the studies were conducted in high income countries with a hand full in Africa. There is paucity of knowledge about the survival experiences of women with cervical cancer in the Ghanaian context. Generally, the literature suggests that cervical cancer survivors have poor physical and psychological well-being but better social and spiritual well-being. Survivors use mechanisms such as prayer, acceptance, faith and hope in God to cope with cervical cancer.

CHAPTER THREE

METHODOLOGY

This chapter presents the research design, the setting, and data collection methods and procedures. In addition, the chapter describes the population and its characteristics, the sampling approach and sample size, data collection method, analysis of data, research rigour and ethical considerations.

3.1 Research Design

Research design is defined as "types of designs of enquiry within qualitative, quantitative, and mixed method approaches that provide specific direction for procedures in a research design" (Creswell, 2014, p.12). In quantitative research designs, the researcher tests a theory by specifying narrow hypothesis and the collection of data to support or refute the hypotheses, and the information is analysed using statistical procedures and hypothesis testing (Creswell, 2014). Qualitative research is an inductive approach to discovering or expanding knowledge. It requires the involvement of the researcher in the identification of the meaning or relevance of a particular phenomenon to the individual.

Analysis and interpretation in this method are not generally dependent upon the quantification of observations (Brockopp & Hatings-Tolsma, 2003). Explorative research investigates the full nature of phenomena rather than simply observing and explaining the phenomena. It provides an insight into comprehension of an issue or situation (Polit, Hungler, & Beck, 2001).

The study employed the qualitative research approach that is exploratory and descriptive in nature and was used to explore and describe the experiences of Ghanaian women who are surviving with cervical cancer. It was essential to use the qualitative design because it helped provide an in-depth comprehension of Ghanaian women surviving cervical cancer.

3.2 Research Setting

Accra metropolis is one of the five districts of the Greater Accra Region of Ghana. It is the capital city of Ghana and the Greater Accra Region and has a land size of about 200 square kilometres with a total population size of about 1,695,136 people and an annual growth rate of 3.36% (Ghana Statistical Service, 2012). Accra is divided into 11 sub-metropolitan areas: Ablekuma Central; Ablekuma North; Ablekuma South; Ashiedu Keteke; Ayawaso Central; Ayawaso East; Ayawaso West-Wuogon; La, Okaikoi North; Okaikoi South; and Osu Klottey. Housing can be grouped into three broad categories: the low income; middle income; and high income areas. The low income housing zones may be divided into indigenous and non-indigenous (dominant migrant) areas.

The indigenes are Gas and their primary occupation is fishing and trading. Accra is cosmopolitan in nature because about 44% of residents are migrants with their ethnic characteristics. Based on this, Accra has a mixed culture. Aside from the Ga language, other languages such as Akan, Fante, Ewe, Twi, and Adangbe are spoken by people in the Accra metropolis. The metropolis has a lot of public and government schools as well as Ghana’s premier University (University of Ghana). In terms of health, there are several health facilities in the metropolis to provide healthcare services including government, quasi-government, mission and private. There are a total of 28 hospitals including the KBTH, 130 health centres/posts and 60 private hospitals in the metropolis.

The radiotherapy centre of the KBTH, located in the Ablekuma Sub-Metro of the Accra Metropolis, served as the outlet for the recruitment of participants for the study. The radiotherapy centre is the first of such centres in the country where patients with various types of cancers are treated.

The radiotherapy centre was commissioned in 1997 to provide radiotherapy (external beam and brachytherapy) services to cancer patients in the southern sector of the country. However, a unit within the centre has been designated for the administration of cancer chemotherapy. The centre has a Cobalt 60 Teletherapy machine; a simulator treatment planning system; a film processor; a C-arm Fluoroscopy machine; two Remote Low Dose Radiation (LDR) machines and Cesium-After Loader for intracavitory application for cervical cancer. Furthermore, the centre has a staff strength of 88 comprising of radiation oncologists, physicists, medical officers, radiation therapists, engineers, nurses, biostatisticians, technicians, and other supporting staff.

3.3 Target Population

Target population in a research refers to a collective number of people the researcher is interested in recruiting for a study (Korb, 2012). The target population for the study were women diagnosed with cervical cancer who were receiving treatment at the National Radiotherapy Centre and Nuclear Medicine of the Korle-Bu Teaching Hospital.

3.4 Sample Size and Sampling Methods

Sample size is the total number of members included in a study (Khan, 2012). Data saturation determined the sample size. Saturation is “when the researcher stops collecting data because fresh data no longer sparks new insights or reveals new properties” (Creswell, 2014, p. 248). A total sample of 15 Ghanaian women with cervical cancer participated in the study.

Sampling is the selection of individuals from a target population who reflects the characteristic of the target population (Khan, 2012). Purposive sampling method was used to select participants for this study. The purposive sampling allowed the researcher to intentionally draw a sample from a population that had the qualities that were expected in the study and therefore members of the population do not have an equal chance of being selected (Khan, 2012). Therefore, the researcher purposively recruited Ghanaian women who were receiving treatment at the radiotherapy centre of the KBTH and were willing to narrate their lived experiences with cervical cancer for the study.

3.5 Inclusion Criteria

The study included: (a) women diagnosed with cervical cancer for at least 6 months; (b) women who could express themselves in the English, 'Ewe' and 'Twi' (local dialects) which the researcher speaks; and (c) women who were receiving treatment at the Radiotherapy Centre, Korle-Bu and were willing to participate in the study.

3.6 Exclusion Criteria

The study excluded: (a) women diagnosed with cancers other than cervical cancer; (b) those who were too ill to participate; and (c) women with cervical cancer with a diagnosis of a psychiatric disorder.

3.7 Procedure for Data Collection

The researcher sought formal permission from the radiotherapy centre of the KBTH with an introductory letter from the School of Nursing, University of Ghana stating the purpose of the study (See Appendix D). The proposal was reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR) (See Appendix E). The researcher presented the ethical approval to the head of the Radiotherapy Centre for permission to recruit participants. At the centre, two nurses were identified by the researcher to help recruit the participants for the study. The researcher explained the purpose of the study to the two nurses, specifying the inclusion and exclusion criteria of the study. These nurses distributed the study's information sheet to the prospective participants. For participants who could not read, the researcher explained the study to them. The researcher visited the radiotherapy centre every Tuesday for recruitment purposes, this being the clinic day for women diagnosed of cervical cancer. The researcher provided her contact number to the nurses so that anytime a prospective participant was identified, she was contacted. Subsequently, the researcher screened potential participants to ascertain their suitability for the study. The women who were found suitable and consented were interviewed at a time and venue favourable to them. Recruitment of participants was done simultaneously with the interviews.

3.8 Tool for Data Collection

A background information sheet and an interview guide were used to collect data from the participants. The background information sheet (See Appendix A) was used to collect information on the participants' demographic data. It covered questions on participants' age, place of residence, marital status, number of children, occupation, level of education, sexual history, duration of disease, treatment type, smoking and oral contraceptive usage history. The semi-structured interview guide (See Appendix B) made up of open-ended questions was used to conduct in-depth face-to-face interviews to explore the experiences of women surviving cervical cancer. The semi-structured interview was appropriate for this study because it gave the opportunity to the participants to freely express their views about the phenomenon and further permitted the researcher to seek clarifications by using probes (Kusi, 2012). The construction of the semi-structured interview guide was based on constructs of the QoL Model Applied to Cancer Survivors and the research objectives as well as the literature reviewed.

3.9 Pre-testing the Interview Guide

Piloting of a research instrument helps in ensuring the efficacy of the instrument to collect the expected responses and also helps in modifying the instrument before it is administered to the participants (Khan, 2012). The semi-structured interview guide was piloted using two women receiving treatment at the Radiotherapy Centre, KBTH prior to data collection. The first two women who expressed interest and met the inclusion criteria were recruited. The interviews were scheduled at times and places convenient to the participants.

Participants received an information sheet (See Appendix C) and two consent forms (See Appendix F). The researcher kept one signed consent form while the participants kept one each. After the first interview, the recorded information was transcribed verbatim before the next interview. The aim was to fine-tune the items on the interview guide before subsequent interviews, check the ability of participants to understand the questions. This enhanced the interviewing skills of the researcher as it was the first time the researcher employed the technique. Data derived from the pre-testing were not included in the actual data for the study.

3.10 Data Collection

Data collection is a systematic process by which a researcher collects relevant information to achieve the objectives of the study (Burns & Grove, 2007). Participants were at liberty to choose the time and place convenient to them for the interviews. The interviews were conducted in English, Ewe or Twi depending on the participant’s choice. The use of participants’ preferred language created an opportunity for the participants to express themselves in their own words so as to gather detailed data (Mayan, 2001; Singleton & Straits, 2010). Data collection commenced in July, 2014 and ended in November, 2014. Each interview lasted between 45 to 90 minutes. Prior to every interview, each participant was guided to complete the background information sheet. This approach helped the researcher to understand each participant’s background, and helped the participants get used to sharing personal details about themselves. The conversations were audiotaped with permission from the participants.

Before the commencement of each interview, the participants were reminded they could refuse to answer any question without reasons or withdraw from the study at any time. They were further assured that their refusal to provide some answers was not going to affect the care they received at the Radiotherapy Centre. The researcher used clear, flexible open-ended questions as well as deliberate silence to allow participants to express themselves and reflect on their experiences. Also, the participants were asked questions which explored their physical, psychological, social experiences and their spiritual well-being. In the course of each interview, responses of participants were probed or redirected whenever necessary to enable their responses to be within the objectives of the study. However, leading questions were avoided. Participants were informed that there may be further interview sessions when the need arises. Each interview was transcribed before the next interview.

Additionally, during each interview, the researcher kept field notes. The field notes contained non-verbal cues such as facial expressions and other key events that occurred in the course of the interviews. At each interview however, a journal was kept noting thoughts, feelings, ideas, moments of confusion, biases and interpretations and observations. This journal also contained the researcher’s personal reflections, emotions, mistakes and successes. All these provided context and background for the study and enhanced data analysis. At the end of each interview, the researcher thanked the interviewee for her participation.

3.11 Data Analysis

Data collection and analysis were conducted concurrently. The recordings on the digital recorder were transcribed verbatim at the end of each interview. The researcher gave each participant a number (for example 001) in order of recruitment into the study. Pseudonyms that started with letter M were used for each participant as well. Names such as Mera, Merab, Merac and Merad were used. Simultaneous data collection and verbatim transcription aided in improving upon the subsequent interview and noting the emerging codes. The researcher ensured accuracy of the manual transcripts by reading and listening to the audio tape recording at the same time. Data analysis began immediately after all the audio-recordings had been transcribed. The field notes added more meaning to the data which further helped to comprehend the entire data set and added context and depth to the data (Mayan, 2001).

Thematic content analysis was used for the data analysis. The transcripts were read severally to identify codes, categories and the primary patterns in the data. A content thematic network was engaged by first reading the transcripts in entirety. Thereafter, the transcripts were read line by line to determine the codes that capture the experiences of the women in line with the physical, psychological, social and spiritual well-being (Mayan, 2009). During the analysis, statements made by the interviewees were compared with other related statements made across all the interviews. Commonalities in each of the individual transcripts were put together by copying the codes into a separately labelled word file on a computer along with the appropriate quotes. This was achieved by looking for associations between the categories. The researcher carefully read and re-read the transcripts to identify common themes. The themes identified were given names differentiating them from each other. The common themes were then grouped from which sub-themes were identified. Subsequently, these themes were analysed (Miles & Huberman, 1994).

3.12 Data Management

The goal of qualitative data management is to organize and store data in such a way to enhance easy retrieval and analysis (Padgett, 1998). The researcher manually managed the data generated from the study. The interviews were transcribed verbatim and those that were done in Ewe and Twi (local dialects) were transcribed in English. This was possible because the researcher could speak these local languages therefore there was no need for a translator. Afterwards, the investigator used pseudonyms to replace the numbers. A six-centimetre margin was created to provide space for writing codes. The researcher kept the hard copies of the transcribed interviews separately from the consent forms. Transcripts were saved with a different file name on a password protected computer.

3.13 Rigour

Rigour refers to trustworthiness in a qualitative study. It is the degree to which the findings of a qualitative study are authentic and its interpretations credible. Credibility, transferability dependability and confirmability have been identified as the major criteria for establishing trustworthiness in qualitative research (Lincoln & Guba, 1985).

Credibility is achieved in a qualitative study when the findings from the data reflects reality and includes activities that increase the probability that credible findings will be produced (Lincoln & Guba, 1985; Carpenter & Speziale, 2007). To ensure this, the researcher purposefully recruited participants who met the inclusion criteria and could provide detailed information on their experiences with cervical cancer. The researcher conducted member checks to confirm the responses and interpretations with the participants at the end of each interview. This was to ensure that their stories were well documented and were a true representation or interpretation of the participant's view. The interviews were coded independently by the researcher and the supervisors in order to identify disparities and these were discussed to reach a consensus.

Transferability, otherwise known as fittingness, refers to the extent to which the findings of the study can be justifiably applied in other similar situations or settings (Lincoln & Guba, 1985). To achieve transferability, the researcher presented a detailed description of the procedure for a participant's selection, the research setting, and the background of the participants used in the study. The researcher also kept the data analysis document and the transcribed data as an audit trail (Padgett, 1998).

Dependability of a research is the extent to which judgment about similarities and differences of content are consistent over time (Graneheim & Lundman, 2004). To ensure dependability in this research, all participants were interviewed using the same interview guide. The researcher also provided a detailed description of the research design, procedures for recruiting participants, and collecting and analysing data in the final report. The researcher gave a report on the background of the participants. All these processes were provided to allow replication of the study.

Confirmability refers to the degree to which the results could be confirmed or substantiated by others. It is to ensure that the meanings given to the data collected are not changed by the prejudices, knowledge, and experiences of the researcher (Kusi, 2012). If a study demonstrates credibility and fitness, the study is said to possess confirmability. In this study, confirmability was established by ensuring that the findings of the study reflected the experiences of the participants and not that of the researcher. The researcher kept a journal to provide context and background for the analysis. There was also an audit trail of interviews and transcripts as well as drafts of the final report. Thus, a systematic collection of documents and recording of activities were done that would allow an independent auditor to come to similar conclusions about the data.

3.14 Ethical Considerations

The researcher sought ethical approval from the Institutional Review Board of the Noguchi Memorial Institute of Medical Research at the University of Ghana, Legon. Permission was also obtained from the KBTH and the Director of the National Radiotherapy Centre and Nuclear Medicine of the Korle-Bu Teaching Hospital with an introductory letter from the School of Nursing (See Appendix D).

At the beginning of each interview, the purpose, objectives and any potential risk were explained to the participants in a language of their choice. Additionally, participants were given an information sheet and consent form. Participants were informed that their participation should be absolutely voluntary. To this effect, the participants were made to understand that they were at liberty to withdraw from the study at any point they wished and they were assured that their withdrawal would not attract any punitive measures. Additionally, participants were made aware that they could decline to answer any question that made them feel uncomfortable. Participants who met the inclusion criteria were asked to sign or thump print two consent forms; one was kept by the participant, the other was kept by the researcher.

The participants' privacy was assured through anonymity. Therefore, the researcher substituted the actual names of the participants with pseudonyms. Furthermore, the researcher removed possible identifying features of each participant in the data to prevent others from identifying participants through their answers. However, the telephone numbers of the participants were collected and saved together with the pseudonyms under lock and key as well as in a password protected computer known only to the researcher. The data was available to only the researcher and the thesis supervisors.

To maintain confidentiality, the researcher adopted some processes. Only the researcher and the supervisors had access to the raw data. The pseudonyms of the individual participants identified the transcripts. All study documents, audiotapes, consent forms, transcripts will be kept confidential under lock and key for at least five (5) years and only the researcher and the supervisors have access to the transcribed data.

CHAPTER FOUR

FINDINGS

This chapter presents the findings of the study. The findings were categorized according to the domains of the QoL model and the objectives of the study. The chapter first presents the demographic profile of the participants, followed by the themes and sub-themes identified.

4.1 Demographic Characteristics

A total of 15 women with cervical cancer were recruited. They were of varied ages with the youngest being 33years old and the oldest aged 67years. All participants with the exception of one had some form of education ranging from primary to tertiary. Nine of the participants were married, two were divorced before diagnosis, one got divorced after her diagnosis, one was widowed, one was in a relationship while one was single. Most of the women had their first sexual encounter between the ages of 13 and 15 years. The majority of the women had between 5 and 7 sexual partners. The sexual partners of the women also had multiple sexual partners. The majority of the women had used oral contraceptives for more than five years. At the time of the interview, four of the women had undergone surgery (total abdominal hysterectomy). Twelve of the participants were receiving both chemotherapy and radiotherapy, while three were receiving only radiotherapy. One of the participants was a Muslim and the remaining were Christians.

The participants have been living with the disease for 1 to 3 years. Two of the participants had no children while 13 had children ranging from two to six. Occupations of the participants included: trading (6); farming (3); teaching (1); catering (1); secretary (1); beauty therapist (1); radio presenter (1); and banking (1). However at the time of the interview none of the participants were working. The women spoke several languages such as English, Twi, Fante, Ewe, and Hausa and lived within the Accra metropolis. The details of the demographic characteristics are presented in Table 4.2 (See Appendix G).

4.2 Organization of Themes

Five major themes were derived. These themes were physical well-being of the women; psychological well-being; social well-being; spiritual well-being and coping strategies; and health system factors. Four themes (physical well-being of women with cervical cancer; psychological well-being of women with cervical cancer; social well-being of women with cervical cancer; spiritual well-being and coping strategies of women with cervical cancer) were consistent with the QoL model while health system factors emerged from the data. Each of these major themes had various sub-themes. In all 23 sub-themes emerged. These sub-themes included those in line with the QoL model and other new ones which the model did not tackle. The themes and sub-themes are presented with verbatim quotations from the participants. Anonymity of participants is maintained by the use of pseudonyms.

Table 4.1 on the next page shows the major themes and the sub-themes that emerged from the data.

Table 4.1: Experiences of Women Surviving Cervical Cancer: Synthesis of Themes and Sub-Themes

Major Themes	**Sub-Themes**
Physical Well-Being of Women with Cervical Cancer	Pain
	Gynaecological Problems
	Gastrointestinal Disturbance
	Body Disfigurements
	Impaired Functional Activity
	Impaired Rest and Sleep
Psychological Well-Being of Women with Cervical Cancer	Anxiety
	Depression and Suicidal Tendencies
	Cognition/ Attention
	Distress of Diagnosis
	Grieving and Fear of Death
Social Well-Being of Women with Cervical Cancer	Impaired Relationships
	Social Isolation
	Economic Burden
	Support Networks
Spiritual Well-Being and Coping Strategies of Women with Cervical Cancer	Meaning of Illness and Acceptance
	A Sense of Hope and Religiosity
	Uncertainty
	The Will to Live (Inner Strength)
Health System Factors	Inadequate Information
	Delays
	Misdiagnosis
	Negative Health Personnel Attitude

4.3 Physical Well-being of Women with Cervical Cancer

Physical well-being refers to one's contentment with life as one experiences the signs and symptoms of cervical cancer and the side effects of treatment. However, the findings of this study revealed that the symptoms of cervical cancer and the side effects of the treatment experience pointed to the fact that the women had a poor physical well-being. This theme embraces all the physical signs and symptoms that the women reported they have experienced in relation to the disease and/ or treatment. This theme is consistent with the Physical Well-Being and Symptoms domain of the QoL model. All the fifteen women in the study indicated that they had some signs and symptoms which marked the commencement of cervical cancer and / or the effects of the treatment they were given. Although the signs and symptoms prompted the women to seek health care at a point, it was realised that all the women could not link the initial signs and symptoms to advanced cervical cancer. A total of six sub-themes emerged which included: pain; gastrointestinal disturbance; gynaecological problems; body disfigurements; impaired functional activity; and impaired rest and sleep.

4.3.1 Pain

The majority of the women experienced pain as part of the disease process. In the narrations of the women, they alleged the pain was felt in their lower abdomen. They described the pain as something that '*moves'* and is severe, equating it to labour pains. Two women commented:

> *"I felt so much pain in my abdomen. It was as if I was in labour and going to deliver, something was moving like a baby in my womb. The pain was as though something was moving, moving and wants to come out from my vagina or anus"* **Mera**

> **"***In fact I will not lie to you, the pain was so severe. Ehh, ehh, the pain was so severe and it was just like being in labour and about to give birth"* **Merad**

To some of the women, the pain they experienced was even more than labour pains, while others could not find the appropriate words to describe their pain. Merac reported:

> *"... Even labour pains during child birth cannot be compared to the pain I was feeling in my abdomen. It is difficult to describe".* **Merac**

Some of the women also had pain in the thigh, waist, back and legs which they described as '*unbearable'*. Merae shared her experience as follows:

> *"At the beginning, I felt severe pains in my thigh, waist, back and legs and the pain was unbearable".* **Merae**

Participants who described their pain as intense alleged they shouted and cried and sometime felt like cutting and throwing part of the body away because of the pain. Meral echoed:

> "*I experienced waist and thigh pain. Whenever I was in pain, I shouted and cried. It was as if the waist was about to come off or I should cut my waist and throw it away, I was in too much pain".* **Meral**

The women indicated the duration of the pain they experienced. In their descriptions, they stated that the pain was continuous. Three of the women said:

> "*If day breaks I will just be in the house, and be experiencing pain which was not stopping*". **Mera**
>
> *"The pain, does not stop, it is always there, every day, every time, no break in the pain".* **Meram**
>
> "*As for this disease and the pain, eiii nothing stops it, whatever you do, the pain will be there all the time, no stopping".* **Meral**

4.3.1.1 Pain Management

In managing the pain, the women indicated using pharmacological and diversional strategies. Some women stated that their doctors prescribed some analgesics for them. According to the women, these were acquired from chemical shops. Others alleged they also bought some over the counter drugs because they felt the prescribed drugs were not working for them. Nevertheless, the women realised that, in spite of these analgesics, they did not achieve absolute pain relief as the medications only worked for a short duration. Three women revealed that:

> *"The doctor prescribed diclofenac suppository for me so that when I was in pain I should insert it into my anus ... when I took the drug the pain was not completely controlled, the pain was still there. The only thing was that, the pain reduced a little like for some twenty minutes and became severe again".* **Merac**

> *" They prescribed some medication for me and I bought them ...in addition, I know some pain killers so whenever the children go to work then I go to buy the medicines and take,".* **Merad**

> *"The drug did not work for long, it works for a short duration and then you have to repeat it again and continue in a similar manner the whole day".* **Meral**

It was further revealed that, aside the pharmacological pain management, the women also utilised some diversional strategies to relieve their pain. One of these strategies was listening to music. Some survivors indicated that they listened to music whenever they were in pain. These songs they believed soothed their pain. Merak shared her experience below:

> "*When I am in pain I will call my sister to start playing songs to me. After listening to these songs for a while, I feel better".* **Merak**

Other diversional strategies the survivors alleged to have employed were applying hot compress to their lower back and assuming a position that was comfortable for them. Merad and Meri had this to say:

> *"Sometimes I put hot towel at my back when the pain starts before I will feel a bit better".* **Merad**

> *"I will lie down in one position before the pain will subside for some time".* **Merai**

4.3.2 Gynaecological Problems

The women also reported having gynaecological problems such as vaginal bleeding, and vaginal discharge as part of the disease process, as well as vaginal dryness and infertility problems which were as a result of the treatment.

4.3.2.1 Vaginal Bleeding

All the women stated they experienced vaginal bleeding. The bleeding differed from copious and continuous to scanty and intermittent. Some of the women described their vaginal bleeding in the following quotes:

> *"Yes the blood was pouring like a pipe. It did not stop"*. **Merac**
>
> *"When the bleeding starts it does not stop at all, it continues for a long time and in large quantities"*. **Merae**
>
> *"I saw blood it was not so much but it was always flowing"*. **Merab**
>
> *"The bleeding was on and off"*. **Merad**

Some of the women also stated that the bleeding was spontaneous and occurred without any activity or triggering factor. Merab and Merae narrated:

> *"Nothing happened, I was there and I noticed that I was bleeding, my whole pant was soaked with blood"*. **Merab**
>
> *"Nothing happened, before the bleeding started, one evening, I felt something like water had poured in between my thighs. I rubbed my hands on my thighs only to have all of my hands stained with blood"*. **Merae**

Conversely, some other women revealed that sexual intercourse and vaginal toileting provoked their vaginal bleeding. Merai and Mera narrated their experiences below:

> "*Whenever I had sex with my husband, I bled a lot*". **Merai**

> *"When I go to the bathroom and in an attempt to wash myself, I insert my finger into my vagina which initiates the bleeding"*. **Mera**

The data revealed that the vaginal bleeding was common to both women who were in their post-menopausal phase and those in their reproductive ages. Some of the women who had post-menopausal bleeding thought their menses were coming again:

> *"I have stopped menstruation so I thought my period was coming back".* **Mera**

> *"When I started bleeding, I thought that the menstruation has started again"*. **Merag**

Women who were still menstruating noticed heavy menstrual bleeding, and irregular and prolonged menstrual flow compared to their previous menstrual histories. Merac and Meram had this to say:

> "*First when I have my monthly period, it does not flow so much but when the disease started my period flows a lot, I bled a lot because I used about five pads a day, my pants will be soaked with blood"*. **Merac**

> *"The last time, my menses started earlier than expected it was not time for my menses but it came and I bled so much, I bled and bled so much for only one day* then *my menses itself started and I bled for 10 days, and that was the first time I bled for 10 days"*. **Meram**

In the narrations of the women, they mentioned that the vaginal bleeding was in the form of clots. The women used words such as '*black like charcoal', 'very big'*, '*very black', 'reddish', 'thread-like"* to describe the clots. Three women shared their experiences:

> "*The clots, the clots, they were black like charcoal*". **Merac**

> "*The blood clots were very big,… they were very black, after the black ones were out, then the reddish clots followed.*

> *Later, other reddish ones in the form of threads also came out"*. **Merae**

> *"… the bleeding was still coming, with clots, clots as big as my fist, they were always black, very, very black. I had never seen that type of thing before"* **Merao**

The duration of bleeding varied among participants. It ranged from a few days through weeks to a month. The duration ranged between three days to one month. Some women shared their experiences:

> *"For 3 days I bled heavily"*. **Meraj**

> *"I was bleeding for two weeks continuously"*. **Merag**

> *"… I was bleeding continuously for about one month"*. **Merao**

The vaginal bleeding affected the women in different ways. Some became anaemic and collapsed as a result of the blood loss through the heavy bleeding and they had to be transfused between 2 - 14 units of blood. Three women who had blood transfusions lamented:

> *"I noticed that the blood started pouring out a lot with clots so I fell down and went unconscious and they sent me to the hospital, they said the bleeding was too much, so they said my blood is too low so they gave me two bottles of blood"*. **Merac**

> *"They gave me three bottles of blood because the bleeding was too much and I was anaemic so they transfused me with the blood"*. **Merao**

> *"I was bleeding every day. That time they said I had severe anaemia. Hmm so they even transfused me with blood. I had fourteen pints of blood"*. **Meraf**

Furthermore, the women stated how they managed their vaginal bleeding. Some of the women used pieces of cloth in place of sanitary pads. Some used sanitary pads alone. It was also revealed that some of the women used diapers in managing the bleeding which they changed several times in a day. The following quotes reflect the descriptions of some of the women:

> *"I used pieces of cloth in place of the pad I use one in the morning and one in the evening".* **Merab**
>
> *"the sanitary pad is useless, the pad is not able to soak the blood for me so in addition to the pad I use pieces of cloth to soak the blood".* **Merae**
>
> *"I used about five pads a day".* **Merac**
>
> *"When I was using the pad, I was using three but when I started using the diaper, I use two in a day".* **Meraf**

4.3.2.2 Vaginal Discharge

Apart from the vaginal bleeding the women experienced, the majority had watery vaginal discharge as well. The discharge was initially colourless and odourless but later became yellowish and offensive. The women used expressions such as '*dead rotten animal*', '*my intestines were rotten'* and *'water coming from a decayed wound'*.

> *"The discharge was like water initially, it had no smell but later on, the colour changed to yellow and the smell too become offensive. The smell was like a dead rotten animal".* **Merab**
>
> "*Initially, the discharge had no colour but with time it became yellowish. The smell of the vaginal discharge was as though my intestines were rotten".* **Meraf**
>
> *"The vaginal discharge smelt like the discharge from a wound; the water coming from a decayed wound".* **Meran**

The women mentioned having the discharge for six to nine months continuously:

> "*The offensive vaginal discharges flowed for about six months continuously".* **Mera**
>
> *"The discharge started about nine months ago and it is still flowing".* **Merac**

Similar to the management of vaginal bleeding, the women used pieces of cloth and sanitary pads to manage the vaginal discharge. They used between three pieces of cloth and four sanitary pads in a day. In addition, the women bathed several times a day. Three women had these comments to share:

> *"I used pieces of cloth, for the discharge then I wash* and *dry them. I change the cloth about three times a day".* **Mera**

> *"In a day I change my pad like four times because of this discharge and because of that I bath several times a day".* **Meran**

> *"I used sanitary pads for the discharge; I used five pads a day. I keep changing it when it is soaked and also baths about 4 times a day. The way the discharge was offensive, I don't feel fine so I just bath as necessary".* **Merac**

4.3.2.3 Vaginal Dryness

A few of the women also said after they have had some cycles of radiotherapy, they noticed they had less vaginal lubrication leading to vaginal dryness whenever they attempted to have sexual intercourse with their partners which caused them pain.

> *"I felt pain so much; I also noticed that I was not very wet. My vagina was dry so we did not even have it for long that day we had to stop suddenly without reaching the peak, the place was too dry and the pain was too much".* **Merak**

> *"After a few cycles of the radiotherapy I and my husband tried to have sex but I noticed that it was like my private part [vagina] was dry, the whole place, was not wet at all. So I was feeling pain in the process so he had to stop at a point because I could not endure the pain".* **Merao**

4.3.2.4 Infertility/ Pseudo-Menopausal Changes

The treatment received by the women affected their fertility hence their inability to bear children. Three of the women had a total abdominal hysterectomy (removal of their wombs). The childbearing needs and the age of the women influenced how they embraced the loss of their fertility. Two of the women who already had children were not worried about the removal of their wombs as they were more concerned about their lives and health. Some of the women reported:

> *"They said its cervical cancer so they have to remove my womb and if they remove it the bleeding will stop. Yes if I am about to die and they remove it and I will live, I will allow and by God's Grace I have four children so I don't need any womb".* **Meraf**
>
> *"I was not worried. All I was looking for is good health. If they will take the womb off and I will be alive I think that is more important. I already have three children, why should I want to keep a womb that nearly killed me?"* **Merah**

A participant who was a Muslim, had no child but had her womb removed. She considered herself as a '*log'.* She said what made her a woman was taken away She lamented:

> *"The doctor did surgery for me and removed my womb, I don't even have a child of my own, I have been married for 5 years now. The doctor removed it. I am like a log, I am not a woman because what makes me a woman has been taken away because of this disease, now when other Muslim women with children are talking how can I contribute? It is only my breast that shows that I am a woman. You see it is the womb that makes a woman feels that she is a woman, what makes me a woman has been taken away, so am I not a man? It makes me sad, how can I leave this earth without having my own child, when I was not getting pregnant I was praying and hoping that one day I will carry my own baby but now I think it is over for me".* **Merao**

The women in this study who were still in their reproductive ages and wished to have their biological children indicated their readiness to resist any approach by their doctors to remove their wombs. Merak and Meran had these comments to share:

> *"The doctor has not said that he will do an operation, even if he wants to remove it I will not agree at all, not today, not tomorrow. I believe that he will not remove it. That is what will make me to give birth so if they remove it how will I be able to give birth again? So I will not agree".* **Merak**

> *"I want to have another child, I have only one child for my husband and he wants more children. He told me he wanted us to have three children and now they are saying that I cannot get pregnant again. I want to keep my marriage so as for the surgery I will refuse, no, I will refuse"*. **Meran**

Also the women who were still in their reproductive ages indicated that they experienced a cessation of their menstruations as a result of the radiotherapy.

> *"My menstruation has ceased because of the machine, it has stopped, till now I have not had my period again for a long time now. They said it is because of the treatment that is why it has stopped"*. **Merak**

Another participant who wished to have more children but had premature menopause narrated how her menstruation ceased because of the treatment she received. She bemoaned:

> *"Now I have two girls. I have not finished giving birth, I love children so I wanted to give birth to four children so I need two more children, but am worried about the way my menstruation has ceased. I don't know if I can give birth when I don't menstruate, in fact somebody must explain to me"*. **Meram**

Some women also indicated they experienced body temperature fluctuations after chemotherapy. They felt cold at one time, then felt too hot at another and had to be changing their clothes to suit the prevailing body temperature.

> *"When I started the chemotherapy, I felt hot sometimes and at other times too I felt very cold, so I was changing my dress. Like in a day, I would wear a sleeveless dress because I was feeling very, very hot and sweating and it was like they have set fire in my whole body. The next moment I will run and pick a sweater and even add my cloth because I was feeling cold"*. **Merac**

A participant who felt hot only shared her experience:

> *"I didn't feel the cold but the heat was what I was experiencing, even though there is an air conditioner there I was sweating. I saw others feeling cold but I felt hot"*. **Meram**

Another participant narrated how she felt cold:

> *"I felt very cold, cold so when I was coming for the treatment [chemotherapy] I always brought a sweater and wore it whenever I began to feel cold, I saw others feeling hot but I felt cold. I will be shivering and shivering"*. **Merao**

4.3.3 Gastrointestinal (GIT) Disturbance

The women reported experiencing GIT problems such as loss of appetite, nausea and vomiting, and diarrhoea as a result of the treatment (chemotherapy and radiotherapy) they received.

4.3.3.1 Loss of Appetite

Some of the women alleged the treatment they received caused their throat to dry and they had sore mouth. These problems, they claimed, made them experience difficulty in swallowing leading to their loss of appetite. Two women had these comments to share:

> *"The medications were making me not feel like eating at all"*. **Merak**

> *"When I started the treatment, I lost appetite. Swallowing of food was difficult because my whole throat was dry and my mouth was sore. The treatment made me loss appetite".* **Merao**

Aside from having loss of appetite resulting from difficulty in swallowing and pain, some of the women's loss of appetite was attributed to the vaginal discharge. One participant stated that her would suddenly lose her appetite whenever she was about to eat and smelt the offensive vaginal discharge.

> *"…whenever I was about to eat and I smelt the discharge I was unable to eat, I lost appetite all of a sudden"*. **Merac**

4.3.3.2 Nausea and Vomiting

All the women had radiotherapy but not all had chemotherapy. They mentioned nausea and vomiting to be the troubling side effects of the treatment they received which made the women weak. Two women stated:

> *"After I came for the injection [chemotherapy], they gave me some medicines to take then I started vomiting, and this lasted for some time. ... I went home and took the medicine they gave me but I still vomited, I vomited a lot and I become very weak"* **Mera**

> *"Whenever I eat at home and came for the injection, I vomited everything. Then I had to eat another food to replace the one I vomited but even that I will still vomit. I experienced both the nausea and vomiting"*. **Merak**

Another woman shared how she vomited after radiotherapy.

> *"After the radiotherapy, I suffered a lot; I vomited, I become weak, hmmm very weak so he [husband] normally brings me and takes me home after the treatment. Sometimes I vomited on the floor at the treatment centre and I begged them to clean it for me*". **Merag**

4.3.3.3 Diarrhoea

Some of the survivors mentioned the passage of frequent watery stool. This, they alleged, was a side effect of chemotherapy and radiotherapy. Some of them indicated that the diarrhoea made them weak. Meran, Merab and Merao stated in the following quotes:

> "*I had diarrhoea too about three times in a day. I did not know it was the chemo that caused it and that day I had to come to the hospital ... I was weak as a result of the diarrhoea. I tried and came and they said the diarrhoea was because of the treatments"*. **Meran**

> "*What I experienced was the diarrhoea and the weakness*". **Merab**

> *"I had diarrhoea, for about three days continuously. I suffered, going to toilet like that"*. **Merao**

4.3.4 Body Disfigurements

The treatment the women received resulted in some body disfigurement as a side effect. These included hair loss, skin changes and weight loss. It was noticed that the women lost their hair after a few cycles of chemotherapy. Also, the skin of most of the women became very dark with rashes and sores. The physical changes are presented in the consequent paragraphs.

4.3.4.1 Hair Loss

In describing their experiences, five women talked about hair loss as a result of chemotherapy. Participants indicated that the hair loss was devastating. Although most of the women were aware that they will lose their hair, they were surprised and '*shocked'.* A participant who had hair loss after her second cycle of chemotherapy expected the loss to be minimal but the hair loss was massive and '*sudden*'.

> *"… After I had my second injection my hair started coming off. I was shocked. I thought it will take a long time before I start to lose them, but it was so sudden. I thought the hair loss was going to be something small, but what I saw was different. When I sleep and wake up my pillow will be covered with my hair. I had a very long hair. It all went off because of this disease. Anytime I saw my head in the mirror, I cried because I have changed. So, I have stopped looking into the mirror"*. **Merao**
>
> *"I noticed a hair loss so I started wearing a wig to hide it from people so they will not see it. Sometimes I used scarfs to cover my hair…. The medicine for this disease is strong, all my hair is off up till now hmmm"*. **Merah**

4.3.4.2 Skin Changes

In terms of changes in the skin, most of the women stated that their complexion changed as their skin became very dark as a result of the chemotherapy and radiotherapy. Mera shared her sorrow:

> *"My skin turned dark. The machine also made my abdomen dark like coal tar. My skin was looking like I was painted with a black colour. My whole body changed"*. **Mera**

Two other women lamented about how their skin changed:

> *"My skin became black; black like this black bag I have here. I am naturally fair. This disease and the treatment have damaged my beautiful complexion"*. **Merah**

> *"I was so surprised at the way my whole skin changed to black, how could I be myself? It was as if I was cooked, just one disease and everything about me has changed. I even stopped looking into the mirror because I was not ready to see how my skin has changed"*. **Merak**

The women mentioned that they had skin rashes and sores around the vulva, vagina and the anal region from the radiotherapy.

> *"I had some skin rashes which I thought were mosquito bites. When I reported to them then they told me it was as a result of the treatment"*. **Merab**
>
> *"I noticed that because of the machine my vagina became sore, sore all over, including my anus, ... , eiii, when I am bathing I cannot insert my finger into my vagina to wash myself, the whole place is full of rashes, blisters, and then they will be breaking"*. **Mera**

A participant also had dry skin from the radiotherapy. She alleged her skin felt as though '*she had no water in her body'*. She had this to say:

> *"You see, when harmattan season comes and the whole skin becomes dry and wrinkled? That was how my body was. It was like there was no water in my body. When I rub my own hands on my body, I felt so dry and wrinkled"*. **Merad**

4.3.4.3 Weight Loss

Most of the women mentioned weight loss as a key concern. They attributed their weight loss to loss of appetite as they could not eat. The women noticed their dresses became loose or bigger on them. The beads around the waists of some women were falling off. Meral, Merac and Merao gave their accounts:

> *"I was not able to eat again. I used to be very fat but now look at the way I have become small. ... Previously, I could eat two balls of 'kenkey'* [local food] *but now I cannot. I do not even have appetite. All my dresses are loose on me. They have been falling off so sometimes I use thread to tie them around my waist. My waist beads were also falling off so I removed them"*. **Meral**

> *"I was looking like a dead person walking about. I cry anytime I look into the mirror. It was as though when I am walking the wind wants to blow me off. I have lost so much weight, I changed totally".* **Merac**

> *"Initially I was weighing 68 kg but now I am weighing 51 kg so you can see that I have lost weight",* **Merao**

4.3.5 Impaired Functional Activity

The women also reported that they experienced impaired functional activity mainly as a result of fatigue and pain. The women expressed their fatigue in terms of extreme tiredness and weakness. Multiple factors were identified that led to fatigue in the women. Among these factors were the treatment they received, loss of appetite, and bleeding.

The women who indicated experiencing fatigue as a result of the treatment they received for their disease narrated that they felt as though they had gone to do a laborious work somewhere. This made them unable to walk even a short distance or to attend to their household chores. Three women reported:

> *"The machine [radiotherapy] made me weak. Sometimes after the machine I cannot walk, I have to sit down for some time to get some energy. When I finish radiotherapy, I feel like I have gone to overwork somewhere, I feel very weak".* **Meram**

> *"Every day after the treatment I feel very weak, I have to sit down at the place for some time before I go. I feel weak like I want to fall down".* **Merao**

> *"Whenever I go there for treatment and I come back home, am unable to do anything because of the weakness".* **Merad**

The women whose fatigue was as a result of vaginal bleeding also said that, coupled with weakness, they felt dizzy. They explained that they easily become tired after walking a short distance and found it difficult to do their household chores. The statements below reflect the women's experiences of fatigue associated with bleeding:

> *"After the heavy bleeding, I felt very weak".* **Merae**

> *"Whenever I bled a lot, I became weak. When I walk a short distance I get tired".* **Merac**

> *"I used to bleed a lot, sometimes I felt like I was in total darkness, the whole place was dark, my joints felt very weak, I could not walk".* **Meraf**

The women who were experiencing the weakness resulting from the vaginal bleeding found it difficult to perform their household chores, maintaining their personal hygiene, or even attending to nature's call by themselves. Hence, they resorted to acquiring assistance. Two women had these comments to share:

> *"As time went on I could no longer do the household chores because I was feeling weak. My daughter cooked and did other things for me".* **Meraf**

> *"... due to my inability to do anything, my sister has come to stay with us so that she can be helping me. She helps me to bath, to go to the toilet, wash my things; she even helps me to dress up. It is like when she is not there I am not there; I am not able to do anything. I am a type of person who wants to do things for myself but because of this disease I have to depend on my sister for everything".* **Merad**

Aside from being unable to walk or work as a result of the treatment given, the data showed that the women also had mobility problems due to the pain, and had to rest periodically. Some of the women alleged they had to rest for a while before being able to continue walking. The pain experienced by some of the women also affected their farming activities. Some women who were farmers could no longer go to the farm to work or carry farm produce home. Mera and Merae shared:

> "*When the pain become very severe, walking was a problem. I could not walk anywhere to do anything. Whenever I got up to walk, I felt severe pain in my legs. When I make the attempt to walk it was as though I was going to fall. I am a farmer but am unable to do my farming work".* **Mera**

> *"Ehh !!! to walk was a problem when the pain was so severe, my legs became heavy ..., if I walk for a short distance, I have to sit down, rest before I can get up and*

> *walk again. I could not carry load from the farm and walk home, I could not walk, because of the pain"*. **Merae**

Additionally, the women were unable to perform their household chores like cooking, sweeping, washing and fetching water because of the pain they experience. These responsibilities were taken up by the children of those who had one. The statements below depict the women inactivity as a result of pain:

> *"Hmmm, I was unable to do the household chores. I couldn't do anything because of the pain. My children did all those things for me. They swept, fetched water cleaned the house,… oh my children they did all those things for me"*. **Meri**
>
> *"I was unable to do anything, I could not do anything because the pain was not allowing me to do anything like sweeping, washing and fetching water or cooking. It was my daughter who was doing all that"*. **Meral**

4.3.6 Impaired Rest and Sleep

The women reported that they had altered sleep patterns. The women could not sleep as the pain was severe at night.

> *"I was not able to sleep because throughout the night I will be in severe pain. It was continuous and was more severe at night"* **Merac**

In addition to the pain, the survivors were unable to sleep because of being worried:

> *"I have not been sleeping at all. I have been thinking. I have been thinking a lot about when the disease will end. I was not like this. Will this disease finish? Why should this happen to me? I think a lot in the night, so I am unable to sleep at night"*. **Merah**

One woman could not sleep in the night because of the vaginal discharge. She was anxious and spent the night thinking about the discharge as she has never experienced this. She echoed:

> *"I don't sleep at all. The time the vaginal discharge was flowing, I was not sleeping at all. I was thinking about the whole thing because I have never experienced that type of offensive vaginal discharge"*. **Meran**

Thoughts of the disease and that of their children kept some of the women awake all night. Meraf said:

> *"I stay awake to about 11pm before I sleep and wake up at 1am. I have been thinking about the disease. The money involved and the children too. It has been a long time since I saw them. All these do not make me sleep. The younger one is only 7 years old. I think about them so I don't sleep well"*. **Meraf**

Additionally, fear gripped some of the participants while others cried in the night which made them not able to sleep. Merao had this to share:

> *"Hmmm, I was not sleeping at all, I could not sleep. I was worried, very worried about what was happening to my life. It was during the night that I had the opportunity to cry. I used the night and the darkness in my room to think about all that was happening to me. I spent the whole night worrying, how can I sleep through those same eyes? I was not sleeping"*. **Merao**

In summary, the data revealed that women with cervical cancer who were receiving treatment were in the advanced stage of the disease and therefore had poor physical well-being as they experienced unrelieved pain, GIT disturbances, gynaecological problems, physical changes, impaired functional activities as well as impaired rest and sleep.

4.4 Psychological Well-Being of Women with Cervical Cancer

Psychological well-being refers to one's contentment with one's state of mind; the ability to share feelings, fears and anxiety as one experiences the signs and symptoms as well as the side effects of treatment for cervical cancer; or a positive mental state.

This theme emerged with five sub-themes (anxiety; depression and suicidal tendencies; cognition/ attention; distress of diagnosis; and grieving and fear of death). Suicidal tendencies, and grieving and fear of death were the two new sub-themes that emerged from the data in this study that were not captured by the QoL model. It became clear that some of the women had anxiety and depression that was due to the associated signs and symptoms of cervical cancer and its treatment effects. Cognition or attention was exhibited by the women as they experienced signs that they were sick; they therefore focused on key signs and symptoms**.** The women were distressed after hearing the news of their cancer diagnoses. Suicidal tendencies were revealed by some of the women because of pain, total dependency on others and news of divorce. It was also noticed that the women were gripped with the fear of death.

4.4.1 Anxiety

The findings of this study revealed that most of the women were anxious as a result of the disease related signs and symptoms such as pain, vaginal bleeding, and vaginal discharge. Some of the women became anxious and worried as a result of the pain they experienced. Merak said:

> *"Honestly I was worried and disturbed. I have never felt that type of pain before".* **Merak**

The data revealed that some of the women became anxious because of the vaginal bleeding they experienced as a disease related symptom. Merac said this in her narrations:

> *"Eiih I bleed a lot, my pants will be soaked with blood, hmmm it was not easy at all I became very worried about the whole thing".* **Merac**

The data revealed that the vaginal bleeding was common to both women who were in their post-menopausal phase and those in their reproductive ages. Some of the women who had post-menopausal bleeding thought their menses were starting all over again which made them worried. Mera and Merag expressed their worries in the following quotes:

> *"I have stopped menstruation so I thought my period was coming back, in fact I was worried, very worried"*. **Mera**
>
> *"I was worried because I thought that the menstruation has started again"*. **Merag**

The women who were still menstruating noticed heavy menstrual bleeding, and irregular and prolonged menstrual flow compared to their previous menstrual histories. This made them anxious. Meram had this to say:

> *"The last time, my menses started earlier than expected, it was not time for my menses but it came and I bled so much, I bled and bled so much for only one day* then *my menses itself started and I bled for 10 days, and that was the first time I bled for 10 days. To tell you the truth I was very anxious"*. **Meram**

Furthermore, it became obvious that the offensive vaginal discharge the women experienced made them women anxious. Merab confessed this in her narration:

> *"The smell of the vaginal discharge was like a dead animal getting rotten. I became anxious about the way I smelt"* **Merab**

Similarly, Meraf and Meran shared their experiences:

> "*The smell of the vaginal discharge was as like my intestines were rotten and this made me anxious". **Meraf***
>
> *"I was anxious about that smelling vaginal discharge"*. **Meran**

4.4.2 Depression and Suicidal Tendencies

Data collected revealed that some of the cervical cancer survivors in this study experienced some form of depression and felt like committing suicide.

4.4.2.1 Depression

It became obvious from the data that the women in this study became depressed because of the vaginal bleeding, weight loss, the skin changes, attitude of co-tenants, unavailability of funds, and loss of fertility. Participants in this study stated that they were depressed because of the bleeding and their mood was low. A participant had this to say:

> *"I was not happy about it at all. The issue is I have stopped menstruating then why should I turn into a nursing mother and be bathing three times a day because of blood? Those things make my mood very low"*. **Merad**

Furthermore, the women who experienced weight loss thought about the cause of their weight loss which made them depressed. As a result, they were not enthusiastic to do anything. Merae had this to share:

> *"Sometimes, the whole day I will be in my room and be thinking about the cause of my weight loss and I become so depressed"*. **Merae**

Merac became sad and cried whenever she looked into the mirror and saw how she lost weight. She expressed

> *"I cry most of the time I look at myself in the mirror seeing how lean I have become"*. **Merac**

Again, the change in the complexion of the skin made the women depressed. They had lowered moods that caused them to lose interest in going to places of interest:

> *"You see I always felt down in my spirit. I was so surprised at the way my whole skin changed to black, how could I be myself? It was as if I was cooked, just one disease and everything about me has changed. I even stopped looking into the mirror because I was not ready to see how my skin has changed, I was always down hearted. I did not have interest in anything like going to interesting places"*. **Merak**

Also, the attitude of co-tenants made some of the women depressed. The co-tenants stared at the women most of the times. They did not bother to wish them speedy recovery. This is reflected in Merak's narration:

> *"The way co-tenants stared at me made me feel uncomfortable and also none of them has ever come to wish me speedy recovery. This behaviour of the tenants made me*

> *very sad and depressed all the time. I am unhappy in that house".* **Merak**

The unavailability of funds for the treatment was a source of worry to most of the women. The women cried as they could not raise the money for the treatment. This made them depressed as Meral and Merae bemoaned:

> *"The other day they said I should pay 1.5 million but I could not raise it so since that day I have been crying every day and feeling so sad".* **Meral**
>
> *"It disturbs me that I don't have money to treat this disease, but what can I do? This makes me sad sometimes and I cry and cry".* **Merae**

It was realized that the women who had their wombs removed as part of their treatment expressed their unhappiness over the loss even though they had children. They felt the womb was their mark of femininity. '*They felt that something has been taken away'*. This made the women sad as the '*hole*' constantly reminded them of their loss of womanhood.

> *"After the surgery, I also noticed that there is something missing from my abdomen; I can feel that something has been taken away. It was like a space has been created. This hole or space or whatever it is always makes me to remember that my womanhood has been taken away, it makes me sad and I am not happy I don't feel complete. I am not happy at all".* **Merag**

4.4.2.2 Suicidal Tendencies

This sub-theme was not captured in the QoL model but was a theme that emerged from the data in this study. Four of the participants voiced their wish to end their lives. Two participants had suicidal thoughts at the initial stages of their pain experience. They felt like taking some medicine to end their lives because of the severe pains. They echoed:

> *"At the beginning when the pain started and was severe, only one thing comes into my mind. That was to look for*

> *some medicine that I could take to end my life, the pain was so severe"*. **Merak**

> *"First when the pain was severe, the drugs were not working, I was taking the drug but the pain was still there, I wanted to die. It was like it was better I die so that the pain and the disease will come to an end"*. **Merac**

Apart from the pain that made some contemplate taking their lives, the thought of being dependent on others for assistance made one of the women harbour thoughts of death so that the care burden on the family will cease.

> *"I could not be on my own, that time I felt like dying so that I will not depend on anybody, if I die I will be free and my sister and everybody too will be free. I will not be a burden on them again".* **Merad**

Another participant stated that she felt like dying when her husband broke the news of their divorce. She thought of hanging herself or drinking a poisonous substance to end her life. She narrated:

> *"At that moment all I wanted to do was to die, take my life, just die. What am I living for? My womb has been taken and thrown away, and now my husband has divorced me in this state, there is no joy. What am I living for, I wanted to die and be free, that was all that was on my mind at that moment. I considered whether I should hang or drink some poisonous thing to die. If my husband is still around me at least I know I have someone to rely on but now that he has left me I just wanted to die, he has betrayed my trust and I just wanted to die"*. **Merao**

4.4.3 Cognition/Attention

The women stated that some signs and symptoms that they experienced made them become aware that they were sick. This realization made them focus on the disease and hence to seek medical attention. The continuous vaginal bleeding prompted the women that there was something wrong with them.

> *"All of a sudden I saw bleeding so I thought that the blood has started coming again, so I waited for two weeks and still*

> *the bleeding was not stopping. I had a doctor friend in a hospital so I went and narrated the whole story to her and she asked me to see a another doctor. After seeing the doctor, they asked me to do a series of test"*. **Merag**

One of the participants came to the cognition that she was sick only when she noticed an offensive vaginal discharge after the continuous vaginal bleeding. This made her talk to her brother who encouraged her to seek medical care:

> *"The bleeding changed to offensive vaginal discharges. With this I noticed something was happening to me. So I told my brother about it so I can go to the hospital… so I prepared and went to the hospital"*. **Mera**

Another woman stated that she found the need to seek medical care only after a member of her church advised her to go to the hospital. Merab narrated:

> *"How can I stop menstruating and start bleeding again? I didn't understand. I sought a church member's view on what it means for a woman to be bleeding after her menopause and she said once blood is coming out, it means there is something wrong somewhere so the person should go to the hospital. I didn't tell her it was me but someone else. I went to the hospital after that so they can tell me what is wrong with me"*. **Merab**

4.4.4 Distress of Diagnosis

The women expressed how distressed they were when they were informed of their diagnoses of cervical cancer. Most of the women became '*worried*' and '*shocked*' upon hearing the news. A survivor vividly said:

> *"At that moment, I was worried and shocked, I even cried"*. **Merac**

A participant narrated how she cried and became annoyed and suspicious when she was informed of her diagnosis because she heard the disease is sexually transmitted and therefore inferred that her husband transmitted the disease to her. She angrily said:

> *"hmmm I became very quiet, placed my head on the doctor's table and cried, cried and cried, I remembered too that they said this disease they don't know exactly what causes it but I*

> *once heard in the news that it is a sexually transmitted disease. When I remembered that the disease is a sexually transmitted, I became annoyed and suspected my husband that very moment. He is the one who infected me I am sure, he is the one. Because I have known this man for about 10 years before we got married. From the time I knew him, I have never had sex with any other man and we have been married for 5 years now and I have not slept with any man, he is the man who has given me the disease, yes he is the one. I did not take this disease from anywhere".* **Merao**

A participant was in a state of denial and therefore did not believe the doctor when she was informed about her diagnosis. Merah shared:

> *"I did not believe the doctor when he told me that I had cervical cancer, I didn't believe him at all, I did not".* **Merah**

In contrast, one of the participants mentioned that she *'felt normal'* when she was informed of her diagnosis because she took it to be a normal disease:

> *"Actually, I felt normal. I took is as any other disease, like going to the hospital and the doctor tells you that you have malaria. You will not say anything, so I didn't do or say anything".* **Merab**

She continued to say:

> *"It was later that when I came here and heard what other women go through with the same disease that I got to know that the disease is a fearful one".* **Merab**

4.4.5 Grieving and Fear of Death

All the women mentioned that they feared they will die from the cervical cancer. The nature of the signs and symptoms made some of the women have a fear of death. Hearing about the demise of other people who died of cervical cancer made some of the women afraid that they will also die. A survivor lamented:

> *"All of a sudden I was afraid of death and it was like I was going to die the next day. You see my mother's close friend died about two years ago and I was told it was this same*

> *disease that killed the woman. I saw how that woman died, she suffered, she struggled before she died"*. **Merao**

Remembering the death of a family member with cervical cancer constantly reminded the women of their impending death. A participant remembered her sister who died of cervical cancer. She said:

> *"I became full of fear all of a sudden that I will die like my sister. … I was terrified remembering that my sister died from the same disease. Anytime I remember my sister in her last days, I fear for my life, I fear I will also die"*. **Merad**

Again, how the public perceived cervical cancer as a disease that kills constantly made the women think about death. Meraf expressed:

> *"Yes I was afraid, I thought I will die because people will always tell you that when you have this disease the only option is death, hmmm"*. **Meraf**

As the women were preoccupied with the thought of death they were concerned about their children. They were troubled about who will take care of their children if they died. Merah moaned:

> *"I was afraid that I will die leaving my children. In fact I wept uncontrollably saying 'God, spare my life for the sake of my children' Yes I was afraid, I was afraid saying who will look after my children? I was afraid, immediately I thought about my children"*. **Merah**

In summary, findings from the study showed that due to the anxiety, depression and suicidal tendencies, distress of diagnosis grieving and death, the survivors of cervical cancer can be described as having a poor psychological well-being.

4.5 Social Well-Being of Women with Cervical Cancer

Social well-being refers to one's contentment with one's relationship with other people around her and her fiscal issues as one experiences the signs and symptoms of cervical cancer and receives treatment. Four sub-themes were identified which are: impaired relationships; social isolation; economic burden; and support networks.

4.5.1 Impaired Relationships

The women's condition and the treatment they received caused marriage problems, family distress, and social isolation. It was realized that survivors who were married had relational problems with their partners. In separate instances there was divorce and separation mainly due to their inability to have sexual intercourse with their partners. Some of the women indicated that they were neglected by their families, and this created relational consequences hence family distress. The children of the women also went through great distress. The women also had relational issues with their co-tenants, co-workers and friends. Socially, the women suffered isolation in their daily lives as they battled with advanced cervical cancer.

4.5.1.1 Marital Problems

Some of the married participants indicated that they experienced tension in their marriages, which was mainly due to the absence of sex. It was noticed that the inability of the women to have sexual intercourse with their partners was as a result of pain, vaginal bleeding, vaginal discharge, and vaginal dryness related to advanced cervical cancer and its treatment.

The majority of the women expressed their inability to have sexual intercourse with their partners because of the pain they experienced. Three survivors shared:

> *"We have not had sex for many months now because of the pain"*. **Merac**
>
> *"Due to the severity of the pain, I always refused to have sex with him"*. **Merah**
>
> *"It has been 1 year since we last had sex because I am always in severe pain so we cannot do anything"*. **Meral**

It was revealed that the absence of sex resulted in quarrels between the women and their partners. In one instance, a woman told the partner to find another woman because she could not continue to have sex with him due to severe pain. Merah murmured:

> *"So due to the severity of the pain, I always refused to have sex with him. He was not happy at all; we had a lot of quarrels… so I told him to find another woman".* **Merah**

Another participant narrated how the husband followed another woman in their neighbourhood because she could no longer have sex with him as a result of the pain. She lamented:

> *"Now I think he has waited for sex for long and he cannot control himself so he has started seeing another woman in the same area we live".* **Meral**

It became apparent from the data that the sex life of some of the women came to a halt when they experienced post coital bleeding. At the time of the interview, some of the women had abstained from sexual intercourse for eight months to two years. This abstinence from sex impaired their marital relationships. Some of the spouses stayed away from home until late in the night while others failed to talk to their wives for days. Others also did not pay for the treatment of the women. The following quotes reflect the attitude of husbands:

> *"After every sexual intercourse I bled ... so because of that we stopped having sex. It has been about 8 months now. That has brought some tension into the marriage. He stays away from home during the day and returns at night".* **Mera**
>
> *"We don't have sex again because of the bleeding. For two years now. Anytime he approached me for sex and I decline he does not talk to me for at least two days because he is angry. So because of that he said he didn't have money for the treatment".* **Merab**

Another woman voluntarily asked the husband for a divorce so she would be free as she could not yield to the sexual demands of the husband because of the bleeding.

> *"I showed him that after the sex I bleed. Every day we fought because I did not allow him to have the sex, I want to divorce so that I will stay alone and be free"*. **Meraf**

Some of the women also reported their marriages were affected because of the offensive vaginal discharge they experienced which prevented them from having sexual affairs with their partners. Most of the women stated they had to abstain from sex because of the offensive vaginal discharges which made them uncomfortable. Two women shared:

> *"We don't have sex again because of the discharge. You see,… everyday vaginal discharges so we cannot have sex. Always there is a discharge. You see it will not be comfortable to have sex in that condition"*. **Merab**
>
> *"The discharge prevented me from having sex, the way the discharge was so much with the smell, we could not have sex"*. **Merac**

A participant also noted she realised there was ineffective communication between her and the partner. The partner did not get close to her because of the offensive vaginal discharge. Meral had this to share:

> *"… I told him that I was the one smelling as a result of the disease. After telling him he … does not get close to me or sit for us to chat again. I always felt depressed because of that"*. **Meral**

The women also reported that they had no sexual desires as they had a lot on their minds. This led to undue arguments with their partners.

> *"Actually I was not thinking about sex. Every day what I think about is this disease, this disease and my life, whether I will die or live. As for sex I did not think about it. I lost interest completely. He said I have changed and that I was not like that previously. So it led to problems in our marriage and he will argue with me for hours"*. **Merah**

Some of the women avoided sexual intercourse because they felt the treatment will not be successful and the disease will spread when they had sex alongside.

> *"Sometimes I feel that when I have not finished the treatment and I have sex the drugs will not work well for me well then the disease will prolong. My private part is where the disease is, so when I go to have sex the treatment will not work and my disease will spread"*. **Merac**

One of the participants also felt she was unattractive to the husband hence did not think of sex. However, she allowed the husband to have sex with her whenever he forced her to in order to prevent the husband from going out to look for sexual pleasure elsewhere. She shared her experience in the quote below:

> *"I feel am not attractive again, as for sex issues I don't think about, it does not come to my mind at all. Sometime he wants us to have sex, a few days ago he forced me and we had sex. I did everything to stop him but he insisted and I allowed him. Maybe if I don't allow him he will go out to another woman, I don't want him to go out"*. **Meran**

In one instance, a woman who had a pre-existing problem of childlessness in her marriage eventually got divorced after her diagnosis of cervical cancer.

> *"We are finally divorced… we have been married for five years but we don't have any child, we have been trying but it has not been successful. This childlessness has always been a source of quarrel between us. So I can say that before I was diagnosed of this disease there was already a problem, the marriage was already shaking, it was like a time bomb waiting to explode, so the marriage has ended"*. **Merao**

Most of the participants relocated and lived separately from their husbands due to the location of the treatment centre. This made them become quite adamant about what could happen to their marriages.

> *"Oh he can go for another woman, as for men, they are like that. Because I have left my hometown and moved to Accra to seek treatment and am not there, I don't know how he is living his sexual life"*. **Merac**

The study also revealed that women who were not married but were in relations had their relationships affected. A participant who was in a relationship which almost led to marriage separated when she told her partner about her diagnosis of cervical cancer. She said:

> *"I once told a man that this is what I am going through so after sometime he lost interest in me and the relationship ended".* **Merak**

However, the data showed that some of the women had no problems with the relationships with their partners even though they could not have sexual intercourse because of bleeding. Meram echoed:

> *"We do not have sex again because of the bleeding…The moment he saw blood after having sex with me, he decided that he will not touch me again. He said he does not want to hurt me again by having sex with me and that once blood is coming out it is not a good sign".* **Meram**

4.5.1.2 Family Distress

The women reported that prior to their diagnosis, their entire family was in great distress. The family waited and anticipated what the outcome of tests was going to be.

> *"In fact, the whole family was worried, we were afraid because we did not know what the lab people will see from the specimen we sent. The whole family was disturbed".* **Mera**

A participant's husband and children were worried because they thought she was going to die. Merag shared in the quote below:

> *"They thought I was going to die. Yes, my husband and children were always looking sad and worried. They thought I will die".* **Merag**

The women who had children indicated that their diagnosis affected their children. Their children were always crying and asking their mothers when they were returning home from the hospital. Merah uttered these words:

> *"The children were always worried about my condition. They always asked me when I will finish the treatment and*

> *come back to them, they have been calling me. They always cried on the phone when they call me. They are so disorganised, when you hear their voice on the phone you can sense that they are so worried"*. **Merah**

A participant said her eldest son took over the management of her business and he was not happy because the business has prevented him from practicing what he has studied at the university. She narrated:

> *"He has completed school but because I have engaged him in my business he has not been able to go out to look for work, he has been complaining but I don't have a choice. He said I am wasting his time because he has studied civil engineering at school but he is not practicing it but sitting in my shop so he is not happy. Sometimes he gets annoyed and will not talk to me but we move on"*. **Meraj**

4.5.2 Social Isolation

It became obvious that the women in this study isolated themselves from social gatherings because of their body disfigurements, vaginal bleeding and vaginal discharge. The body disfigurements resulting from the treatment affected their appearance, which led to body image concerns. This subsequently prevented them from being involved in social activities. The body image concerns leading to social isolation are presented in the ensuing paragraphs.

The hair loss, according to some of the women, made them stay away from social gatherings because they felt their appearance had changed. They stated that they preferred to stay indoors to avoid questions from people. Two survivors said:

> *"When people who knew me saw that I was always wearing wigs and using the 'hijab' they were asking why? So to avoid all these questions, I preferred to stay indoors"*. **Merao**

> *"Yes I noticed a hair loss….. It makes me look ugly. If I do not wear the wig or the scarf people look at me everywhere I passed. Because of that I have stopped going to social gatherings"*. **Merah**

Most of the women who also noticed their skin have become very dark as a result of the chemotherapy and radiotherapy stayed away from social gatherings. They explained that they felt their appearance drew the attention of others. Mera and Merah narrated:

> *"My skin turned dark. I could not go anywhere. My skin was looking like I was painted with a black colour. I can't be going out to town like that; because with the black skin everybody will sense I was not normal. My whole body changed"*. **Mera**

> *"My skin became black. I am naturally fair so when my skin changed everybody who knew me noticed that something was wrong with me. The dark skin sells you out to people that all is not well with you. This disease and the treatment have damaged my beautiful complexion and my appearance, it is better to stay indoors"*. **Merah**

Most of the women also mentioned weight loss as a key concern that prevented them from taking part in social gatherings. The weight loss affected the physical outlook of the women, which was a matter of concern to them. One woman stopped going to the mosque to avoid questions from people because of the weight loss. She was uncomfortable with the way people stared at her and this made her resolve to stay at home. She reported:

> *"Hmmm, I stopped going out to the mosque and other places to avoid people looking at me and asking me questions like what is wrong with you? Why have you lost weight? The way people were looking at me, I became uncomfortable and most of the time I want to stay indoors"*. **Merao**

Some of the participants had the impression that their husbands did not admire them anymore because of the weight loss. Meran who felt unattractive to the husband murmured:

> *"My husband even complained that I was losing weight after commencement of the treatment. When he said that, I felt he did not like my physical outlook, oh I have really changed"*. **Meran**

Because the women felt unattractive, they avoided being naked before their partners. They were hesitant dressing up after bathing anytime their partners were in the room because they felt ashamed of their weight loss.

> *"It is shameful, when I am in the room with my husband. I make sure I am in my dress. I do not want to be naked; I look too horrible. Whenever my husband is in the room after I finish bathing, I will not dress up until he goes out. All was because of the way I was looking. I was like bones. I am not attractive again. I have lost so much weight"*. **Meraf**

The body disfigurement not only severed the relationship between these women and their spouses but with their co-tenants as well. Some women indicated that their co-tenants stared at them and at times entered their rooms when they saw them coming. Merak shared her experience with her co-tenants. She narrated:

> *"When the people in the house are sitting outside and they see me coming, they enter their rooms. I do not know why they behave in such a manner so I decided to be in-doors all the time so they would not see me".* **Merak**

Aside from the problems some of the women had with their appearance that made them isolate themselves, the narrations of the women who experienced vaginal bleeding also revealed that it caused them to stay away from social gatherings such as birthdays, church and weddings. This made some women unhappy as there was no joy or happiness in their lives. Three women announced:

> *"Some time ago, a birthday party was organised for our grandfather, I could not go because of this bleeding".* **Merad**
>
> *"The last time I went to church and before I realised, I stained my cloth at the morning devotion. The cloth was soiled by blood so since then I stopped going to church".* **Meraf**

> "*Am afraid I will soil my dress because I bleed often, so I don't go anywhere, am always in doors, I was not feeling happy at all. I miss all those parties and weddings and it is like there is no moment of joy and happiness for me"*. **Meraj**

One woman could not go to church because of the bleeding. According to her, women who bleed were not allowed into the chapel. They were made to sit at a designated area. She said:

> *" I worship with a church where if you are bleeding you will not enter the chapel, there is a place for bleeding women and that area is mostly full of young ladies who are still menstruating. So as an elderly woman if I go to sit there, everybody will know I am sick so am unable to go to church, I stay at home".* **Merae**

A participant narrated how her relationship with co-tenants was negatively affected because she was bleeding. The co-tenants stared at her and did not want to share the bathroom with her. The co-tenants bathed before her or went to nearby houses to bathe if she had used the place. Mera shared her experience:

> *"They watched me closely, they knew I bleed. I noticed they don't want to share the bathroom with me. Either they wake up at dawn and bathe before I wake up or they will go to nearby houses to bath. In fact the attitude of co-tenants made me think a lot at that time. Nobody wanted to talk to me. This sickness has made me very lonely in the house in which I live"*. **Mera**

Furthermore, the offensive nature of the discharge some of the women experienced affected their social lives. They isolated themselves from social meetings such as church and marriage ceremonies.

> *"Am also unable to go out because of the smell and the fear that I will soil myself. It prevented me from going to church during those times and attending occasion like marriage ceremonies*". **Mera**

> *"Hmm am not able to go anywhere, because I know the way this water smells when I go to a gathering, they smell it and*

> *everybody will be looking at me. I was always smelling, all the time I was smelling".* **Meral**

A participant who attempted to attend church while experiencing the offensive vaginal discharge on an occasion sat on an isolated seat away from the congregation to avoid other people. She indicated how she isolated herself in this quote:

> *"I was always feeling that when I got close to people they may smell the offensive discharge so I always stayed away from people and preferred to be alone. When I am going to church I get scared that I will soil my dress but I want to go and pray to God so He will heal me. So I go late so that I can sit at the back seat in order not to mingle with others".*
> **Merac**

In addition to the above, some of the women noticed that their colleagues at work were not comfortable with their presence and will do everything to avoid them. Merak mumbled:

> *"I can see from the attitudes of some co-workers towards me that they are uncomfortable with me. Oh, before I became sick, when it is time for lunch, one person will go round and ask all of us what we will eat. But since they got to know I am sick, some of the people do not want to talk to me. They will not come and ask me what I will eat if it is time for lunch. When I also go round to find out what they will eat they will refuse to tell me. I went to one of the offices and the moment I entered, people picked their phones and one also entered the washroom. They tell you indirectly they are not ready to talk to you".* **Merak**

4.5.3 Economic Burden

It was evident that the diagnosis and treatment of cervical cancer had a tremendous financial toll on the women and their families. Factors such as cost of treatment, living expenses and work were identified. The cost of treatment was high and this made some of the women take a loan to enable them meet their treatment needs. Others could not meet the financial demands of the treatment for cervical cancer hence had to fall on others for help. Where the women had no help, they were left to their fate. Due to the physical impact of the disease, all the women had to stop work. While most of the women who were gainfully employed still enjoyed full salaries, those participants who were self-employed had their businesses folded up thereby worsening their financial plights.

4.5.3.1 Cost of Treatment

The women indicated that the cost of treatment for cervical cancer which included radiotherapy and chemotherapy as well as regular laboratory investigations and other medications for symptomatic treatment was high. A participant had this to say:

> *"It is very, very expensive. The machine cost me 1,480 Ghana cedis and the chemo cost 108 Ghana cedis every week but I heard it has been increased to 155 so I will start paying the 155 weekly. After all these, the cost of the lab investigations and other medicines that you have to buy for example, when you have headache or diarrhoea, loss of appetite and all that"*. **Merac**

Due to the high cost of treatment, the children of some of the women had to borrow money from others to enable the women to have treatment. The women appealed to the government to extend financial aid to women with cervical cancer:

> *"One of my children is not working but she borrows from people, which she has not paid. She still owes people. What I can say is that, the government should help people who suffer from this disease with some money to be able to treat the disease. The money involved in treating this disease is so much"*. **Mera**

A participant who had to take a bank loan for her treatment said-

> "*I have spent a lot of money. I had to go for a bank loan to continue the treatment".* **Meraf**

Another participant who could not raise the money for her treatment had to stop her treatment. She bemoaned:

> *"The cost is high; because of that all my money is finished. The other day they said I should pay 1.5 million but I couldn't raise it so since that day I have been crying every*

> *day and I feel so sad. So I came to plead with them that I don't have the money so they should use the little that I have been able to pay for the radiotherapy for me. They said they don't treat for free so I am not able to go for the treatment again"*. **Meral**

4.5.3.2 Living Expenses

In addition to the cost of chemotherapy, radiotherapy, laboratory investigations, and medications for symptomatic treatment, a lot of money is spent on the daily transportation to and from the treatment centre and on feeding. Merae gave this account:

> *"I take a car every time I am coming to the hospital for treatment, transportation is not easy. In and out every day from where am staying is 10.70 Ghana cedis daily. It is a lot of money. In fact money issue is my major problem. I do not even have enough for food"*. **Merae**

Similarly, Meraf shared that:

> "*Anytime I am going for treatment, I take my eldest son along. From our house to the treatment centre is far and transportation cost in and out cost 10 GHC for one person so when you multiply that by two you can see that it is expensive. Apart from that when we come we have to eat; all these things cost a lot of money"*. **Meraf**

In addition to the cost of feeding and transportation to the treatment centre, the cost of accommodation in the city was a burden for some of the women who had no relatives in Accra.

> *"I am not from Accra; I don't have a home here. I don't even have a relative here so when they asked me to come here for treatment I had to come and look for a place to stay. I found the mothers hostel and I pay 6 GHC every day. I have been here for two to three months now. It is a lot of money. I cannot be travelling from my hometown to the treatment centre every day; I just have to stay here in Accra so that it will be easy for me. This* accommodation *takes a lot of money"*. **Mera**

4.5.3.3 Work

The majority of the participants who were self-employed had their businesses shuttered. They could not manage the businesses when they got sick. The main source of income for the women crumpled because they used the money meant for the business for treatment. Two women who had their businesses collapsed said:

> *"I get every money from my work, my work, my business. So now that the business is down there is no money, I have used all the money to do the treatment. I want to live so if I am alive and the business is down, it is better for me than to keep the money and die. So now my business is almost collapsed. When I get something from the business I bring it here for treatment".* **Meraj**

> *"Am unable to do my business the whole business is down, very down. I can't go to sell fish again. If by God's grace I am fine after the treatment, then I will start the business again, my whole business is spoilt everything, my money; all is gone with this business".* **Merai**

4.5.4 Support Networks

The majority of the women acknowledged that the support they received from spouses, workplace, friends and family had been the reason for their continual existence. Although most of the women received support from their spouses, not all the women received spousal support. Also, the spiritual and financial support they received from significant others helped them to go through their experiences with advanced cervical cancer. The sub-themes were spousal support, family support, workplace support and spiritual support.

4.5.4.1 Spousal Support

Nine of the women were married, and three were divorced at the time of the study. It is important to note that two of the women were divorced years earlier before they were diagnosed of cervical cancer while one of the women divorced after she was diagnosed.

Only three of the married women were staying with their husbands and the other six had travelled from other parts of Ghana to the city (Accra) for treatment.

Most of the women whose husbands were far away stated that they received encouragement from their husbands whenever they communicated. A participant said:

> *"Now that I am here he calls me. He calls and tells me to be courageous and that everything will be fine. He also says whatever God does come at its apportioned time so this disease will go and we will be happy again"*. **Merah**

Furthermore, the women received physical care, and social and emotional assistance from their husbands, and at times the husbands accompanied their wives to the treatment centre. She echoed:

> *"He suffered very much when he cared for me. Even at first, he has been bringing me to the radiotherapy centre. Oh he is always there for me. He will be massaging my legs for me every evening. Anytime am going for treatment he will accompany me to the hospital for treatment. That is why am saying he has cared for me"*. **Merag**

Additionally, some of the women said they received spiritual support from their husbands-

> "*He has done very well, he has done very well, he was always praying for me to get well". **Merag***
>
> *"He is praying that I get healing and strength"*. **Meral**

Some of the women indicated that their husbands helped them domestically by washing, cleaning, cooking, sweeping and fetching water. Two women narrated:

> *"He cooks, washes for me, cleans and fetches water"*.
> **Merac**
>
> *"At the beginning when the thing was serious, my husband cooked, fetched water for me to bath and swept the house"*.
> **Merah**

Some of the women further stated that their husbands have been the sole source of their financial support. The women depended on these finances for their treatment and other needs. Merab and Merai gave their accounts. The following quotes reflect the experiences of two women:

> *"Everything I need my husband provides it. My husband has been of so much help to me. He has always been there, he provides all the money I need for my treatment and other things"*. **Merab**

> *"My husband, only my husband supports me with money for the treatment. There is no other person. Whenever I need money here I call him on the phone and he sends the money to me"*. **Merai**

In contrast to the above, some of the women have never received any financial support from their husbands since they have had the disease.

> *"Since my sickness my husband has not even give me 10 pesewas to buy water"*. **Mera**

> *"Oh for him once I mention money then he will say there is no money so it has all been through my toil so far that I have come this far. He has never even given me transportation to the treatment centre for my treatment. He has never given me a pesewa for my treatment. How can I be calling this man my husband? He has never given me any money, I wake up from the same room with him and after dressing up to go to the hospital he will say go well and come back in time. Sometimes by the time I finish bathing he will quickly leave the house without my knowledge because he wants to avoid giving me money. In fact it is not easy for me"*. **Meral**

Again, some of the women said they received informational support or advice from their spouses. Husbands suggested that the women sought healthcare in the hospital.

> *"He told me to go to the hospital. He told me that the way I was experiencing the symptoms it is an indication of a bad disease to I should go to the hospital. It means he was concerned about me"*. **Merac**

> *"He … suggested that I went to the hospital. When he said that I was happy. It made me think he cared about me"*. **Meram**

On the other hand, a spouse also advised the wife to go to herbal doctors to seek treatment for advanced cervical cancer.

> *"Earlier he said we should use herbal medicine but later he said I should go to the hospital. After I came here he said I should come back and use herbal medicine but I did not mind him"*. **Meraf**

4.5.4.2 Family Support

Traditionally in Ghana, the family plays a key part when one requires help. The majority of the participants stated that they received financial, emotional and social support from the relatives (mother, brother, sister and children). The financial support some of the women received helped them to pay for the treatment. These words from a participant explained it:

> *"My siblings … and their children contribute money for me. Had it not been my family members and my children who supported me financially, I would have died. Yes, they helped a lot, my siblings and their children helped my own children also supported me. The one I followed really helped"*. **Mera**

The women also received emotional support from their families as some of the relatives cried to show their support.

> *"Oh my children, everybody, the whole family was good to me. They were good to me"*. **Merag**

A participant did not receive any family support. The family never cared for her as they were of the view that she is married and therefore must receive all forms of help from her spouse. She said:

> *"My family are aware, they are aware but none has ever assisted me financially, they are a lot, they are so many but none has helped me, none of them cares about me. They said because I am married my husband should look after me and*

> *that once I am married it is the man's responsibility to look after me when I am sick".* **Meral**

4.5.4.3 Workplace Support

Some of the women who were gainfully employed had support from their managers or supervisors and co-workers. The women were unable to go to work but received their salaries as full time workers. Their managers and some co-workers called them to find out how they were faring. They were not left out of anything that was shared at the workplace. Some employers even paid the hospital bills of some of their workers afflicted with cervical cancer. Merak shared her joy:

> *"The time the sickness was serious, I stayed at home for months … when I come for treatment and I feel I cannot go to work, then I let them know that I cannot come. Even if I am unable to go to the work when the month ends they pay me my salary as a full time worker. They pay the hospital bills for me".* **Merak**

She further said:

> *"Yes some of my co-workers call me to find out how I am doing if I am unable to go to work. Especially those I am free with at work, they call me regularly. My manager too calls to find out how I am doing. Even if he does not call me directly he finds out from my close friend at the work how I am doing. Even if they share something at the work like rice and sugar and those things they give me my share too. Everything they share, I get my portion".* **Merak**

Some of the women mentioned that their supervisors at work advised them to take formal leave for the treatment so they will secure their jobs and also enjoy their monthly salaries.

> *"My superior at work knows I am not well. It was even my boss who advised me to take leave for the treatment so that nobody will use it against me or sack me from the work. So I did and every month I take my salary".* **Meram**

A participant who was an employee in a private establishment felt her manager was *'wicked'* to her because she was made to resign from her work because management could not pay her anymore. She lamented:

> *"I decided to take sick leave which was granted. After the sick leave I decided to take a part leave because I was still not fine, it was at this point that my employer asked me to resign because he cannot continue to pay me. ... The manager ordered that they paid me three months' salary and I resigned from the work. My manager was too wicked to me"*. **Merao**

Some of the women also had very cordial relationships with their co-workers. They received calls and visitations from their co-workers which made them happy. Some of the women said:

> *"They called me on the phone and also came to visit me to see how I was faring. They donated money and gifts for me. This made me happy"*. **Merag**

> *"I do not work there again but they still call me and once in a while they come to visit me. When they come we share funny moments we had then in the office and we laugh. It helps me a lot"*. **Merao**

4.5.4.4 Health Workers' Support

Generally, the women described the attitudes of the nurses who administered chemotherapy to them; saying that the nurses treated the women humanely which made the women happy. Two women who were happy with the attitude of some nurses shared:

> *"At the chemo place, whenever you come they relate to you nicely. They relate with us well especially those at the chemo unit. When the intravenous line is on you and you feel like urinating, they will stop it for you to go and urinate and they will reconnect it for you when you return, they do well and I am happy about that"*. **Merad**

> *"Oh they are working well, like when you are doing the chemo and the drip is finished they quickly come to change it for you when you call them. If you also feel that the drip has stopped flowing or something is happening and you call them they will come so they are doing well"*. **Merak**

Others were of the view that the nurses were '*smart'* and '*friendly'* to them which made them happy.

> *"They are smart in caring for people and they are friendly too, it makes me feel happy"*. **Merac**

As a summary of the social well-being of women with cervical cancer, the findings showed that all the women in this study were in the advanced stage of the disease, which affected their social well-being in totality. Even though most of the women enjoyed tremendous support, it was noticed that women had impaired relationships, social isolation, economic burden, and family distress. Based on these findings, it can be concluded that women with cervical cancer have poor social well-being.

4.6 Spiritual Well-Being and Coping Strategies of Women with Cervical Cancer

Spiritual well-being refers to a sense of inner peace and a search for meaning as one experiences the symptoms and side effects of the treatment of cervical cancer. Even though coping was not part of the model, the women described their spirituality as a way of coping with cervical cancer. Coping strategies are self-adopted approaches employed by women surviving cervical cancer in order to live a meaningful life as they experience the symptoms and treatment side effects. The findings from the study showed that women surviving cervical cancer tried to find inner peace, and adopted ways of coping with the symptoms and the treatment side effects. This is an indication of a good spiritual well-being.

Sub-themes such as meaning of illness and acceptance, a sense of hope and religiosity, uncertainty, and a will to live (inner strength) were identified. It was evident that the participants derived meaning from their illness. Again, narrations of the women revealed high religious beliefs. Even though the women could not attend regular church services due to the physical consequences of cervical cancer, the women took interest in other religious activities such as prayer, reading the Quran and the Bible, and listening to the word of God and inspirational songs. Furthermore, it was obvious that the women had hope in God. Their faith in God made them look up to God for their healing. The women had excessive uncertainty. A will to live (inner strength) featured strongly in the accounts of the women. Subsequently the sub-themes are presented with verbatim quotes from the participants.

4.6.1 Meaning of Illness and Acceptance

In their narrations, some of the women sounded superstitious. They thought the disease was being caused by evil spirits. Meral and Meran had similar thoughts:

> "*Somebody told me the disease was caused by someone through juju". * **Meral**
>
> *"When the disease started I felt somebody has done juju on me because I didn't understand. When I was pregnant I suffered throughout and after delivery just after a year that I thought I will put myself together and start my business then this disease too started. So, I felt somebody has done something to me but I have no idea who that person could be"*. **Meran**

Others thought they were '*bewitched',* a thought that close family members and friends shared. Merah had this to say:

> *"Because I didn't know what was happening to me I thought someone was bewitching me. The people around me [friends and family] also said they were sure that someone was bewitching me. So they said I should go and look for the source of the disease from native doctors"*. **Merah**

Another woman who lost a sister to cervical cancer previously thought the devil is waging a war against her family. She also felt she had the disease due to the sins she might have committed:

> *"At that moment I had the feeling that an evil spirit is behind all these targeted at my family. Sometimes, I felt that the disease was caused by the sins I previously committed"*.
> **Merad**

The survivors indicated that they accepted the disease as their fate hence they looked up to God to heal them. Accepting the diagnosis was a source of strength to the women.

> *"Yes I have accepted it so I have given all to God looking up to Him for healing. I know He will heal me, He has healed a lot of people; so why not me? All I do is to pray, have faith, believe and look up to him"*. **Merao**

This acceptance made the women continue with their treatment schedule as presented by the quote below:

> *"Oh, I can say that when they told me that was the disease I said ok. I made up my mind that I will do all I have to do to get my healing is what I have been doing. Anytime it is time for treatment I make sure I come, I don't miss at all"*.
> **Meram**

Some of the women declared that the experience they had from cervical cancer has made them trust in God more than ever, they read the word of God more often than before the illness. Mera stated:

> *"I have realised that even though I don't go to church often, I trust God more. I read the bible often, and I always pray. I can say that the disease has made me to trust God more"*.
> **Mera**

In addition to trusting God more than before, a participant also revealed that her experience with the disease caused her to be more compassionate towards people who are ill because she has come to appreciate what they go through. She has also become a '*patient*' person:

> *"Now I love God more and I even become more sympathetic towards people who are sick. I know what they go through. I have become loving, I now love people more. I also see life differently, I have become patient and very calm, and this is*

> *one of the positive things that I have gained from this disease"*. **Merao**

The experiences of cervical cancer have made some of the women develop a passion to help other people as human beings need help:

> *"This disease has made me to see life differently. Now all I want to do is to share and help people. I want to do that because this disease has taught me that we all need help. The way I am suffering I just want to be helping people, I don't even have to be worrying unnecessarily about life, and we all have to relax in life"*. **Merae**

4.6.2 A Sense of Hope and Religiosity

It became apparent from the study that the experiences of the women after being diagnosed of cervical cancer increased their hope and faith and they became very religious. The participants clearly demonstrated their hope in God. They had the hope that God will heal them but not a herbalist. Two women stated:

> *"I know God will heal me. I do not have faith in anybody apart from God"*. **Merab**
>
> *"I tell God He is the only one who can heal me and I do not have anywhere to go for healing, and no herbalist can heal me. Even the doctor said so. To me it is God, the son Jesus Christ and the mother who can heal me. So all the time, that has been my prayer or my words to them, every morning and evening".* **Mera**

Additionally, the women believed that God will heal them through the doctors and the nurses. They were of the view that God will give the nurses and the doctors the knowledge and the wisdom. Mera shared:

> *"No human being can heal me. He (God) created me onto this earth and even if doctors and nurses will heal me, He (God) will have to talk to them, give them knowledge and wisdom to be able to heal me".* **Mera**

It was further revealed that the improvement in the condition of the women increased their hope that they will be healed. This quote explained Meram's hope:

> *"Yes I have so much hope that I will be fine. Because I have noticed that, the way I came I am not like that again, I have seen improvement. I have so much hope, I have hope".*
> **Meram**

Some of the women also had hope that they will be healed because anytime they listened to the experiences of other women, they thought their own experiences were better. One survivor had this to say:

> *"Yes I have hope that I will not die but live. Whenever we meet here as women, we communicate. ... Through that I even realised that my situation is better than others. Others have more severe presentations than I experience".* **Merab**

The women became concerned with religious activities. According to them, these activities helped them to cope with their diagnosis. Prayer was paramount among these religious activities because some of the women thought the prayer helped them cope with their pain and kept them alive. Merak and Meral used prayer to cope with her disease. They narrated:

> *"When the pain starts I begin to pray in my head and I will feel better"*. **Merak**
>
> *"Yes I pray and it gives me strength without which I know I would have died long ago. Anytime I pray then my spirit tells me that I will not die and whenever I finish praying I feel that I have gained some strength so because of that I pray every day, it has been helping me".* **Meral**

Furthermore, all the survivors in the study reported that the spiritual support they received from significant others made them move on with their experiences with cervical cancer. The spiritual support came in the form of prayer from their family members. This is reflected in the quotes below:

> *"My family have been praying for me, they read the Quran for me"*. **Merao**

> *"My siblings pray for me and also give me hope that I will be fine"*. **Merah**

Some survivors were offered prayers by their spiritual leaders for healing. The survivors acknowledged the spiritual assistance in the following quotes:

> *"I go to church on Fridays and my religious leader prays for us for healing"*. **Mera**

> *"Anytime I am unable to go to church, my children will tell the pastors and some prayer warriors in the church. So after church they will come to the house and pray for me. At times, they will visit me twice in a week to pray for me so that God will heal me. They were helping me a lot"*. **Merad**

Aside from being prayed for by religious leaders, some survivors said religious groups visited and offered them prayers for healing. Merak narrated:

> *"Oh I am in Christian Youth Builders in the church, they come to visit me in the house and pray for me all the time for God to heal me."* **Merak**

The women further stated that reading the word of God became a regular activity for them. A participant of the Muslim faith read both the bible and the Quran. She said:

> "*Anytime I think of all that has happened to me and all the changes that have taken place in my life then all I do is to read the Quran and sometimes I read the holy bible. Before the illness, I didn't read the word of God regularly, but now I do. I have some special texts that I read from the holy bible to help me in this difficult moment e. g. Psalm 118: 17 – 'I shall not die but live and declare the works of God', another one too is John 5: 24 and it says 'we have passed from death to life'. When I read all these verses they make me strong, another powerful text is Hebrews 2: 15 says – 'and free those who all their lives were held in slavery by their fear of death"*. **Merao**

She further reported how she used spiritual objects to demonstrate her religiosity.

> *"One thing too I do that helps me to move on is to wear the 'abaaya' [long dress for Muslims] and sleep on the 'sajaadah' [mat for prayers], the moment I do all these I know healing is taking place in my body"*. **Merao**

Other survivors said they had the privilege of enjoying inspirational songs from religious groups, which gave them strength to sail through their experiences. Merak verbalized:

> *"The Christian Youth Builders in my church also visit me in the house and we sing together before they leave"*. **Merak**

Although church attendance is considered a key religious activity, it became obvious that the majority were unable to attend church as they used to do before their diagnoses because of the associated signs and symptoms such as pain, vaginal bleeding, vaginal discharge and some of the treatment consequences of cervical cancer.

4.6.3 Uncertainty

The women expressed their uncertainties in the areas of work. Meran who was unsure about her work expressed her uncertainty in the following quote:

> *"I think about my work. I do not know if I will be able to practice as a hair dresser again because I am losing all my customers one by one I don't know, I don't know, I have been thinking about my work. I don't know if the work will move on well again by the time I have finished the treatment for this disease"* **Meran**

A participant who got divorced after her diagnosis of cervical cancer was not certain about marrying again. She muttered:

> *"My marriage, I don't know if I will marry again, after the pain and the heart breaking moments I experienced, am not sure I will marry"*. **Merao**

Some of the women further mentioned that they were not sure whether they will live or die. They felt they will die but do not know when. Two survivors said:

> *"I don't know whether I will live for 1 year or 2 years, I do not know"*. **Meraf**

> *"Whether I will die or not, I don't know, my mind tells me all the time that I will die, I will die, I will die".* **Meraj**

4.6.4 The Will to Live (Inner Strength)

The majority of the women in this study demonstrated tremendous inner strength. The women had the will to live, which they felt made them move on.

> *"I want to live. I don't want to die again. I want to live and will do everything possible to live and stay alive".* **Merao**
>
> *"Something in me tells me that I will not die and I also tell myself I will not die. I will live and proclaim the goodness of the Lord. I will live and live, my spirit tells me that every day".* **Meram**

Some of the women stated they wanted to live for their children. This thought of their children seemed paramount in their will to live.

> *"When I see my children, I want to be alive so that I will see them grow up. They are still young and they need me as their mother, I need to be alive for them, When my mother died leaving me in the hands of my stepmother I suffered so I want to live and care for my children myself that is what I tell myself every day that I want to stay alive, I will live to proclaim the goodness of the lord".* **Meran**

In summary, the women surviving cervical cancer had faith and hope in God. The survivors looked up to God for their healing. Additionally, the women adopted other ways of coping with their disease. These strategies could aid them to achieve a good spiritual well-being in general.

4.7 Other Pertinent Findings Impacting on the Well-Being of the Women

The data revealed that apart from cervical cancer and the treatment that affected the well-being of women surviving cervical cancer in entirety, there were factors in the health system which influenced the well-being of the women. One theme identified was health system factors.

4.7.1 Health System Factors

This theme captures the activities of healthcare providers at the point of healthcare delivery, which could affect the well-being of the women. The four sub-themes that emerged were: inadequate information; delays; misdiagnosis; and negative health personnel attitude. These sub-themes are presented subsequently with verbatim quotes from participants.

4.7.1.1 Inadequate Information

The study findings showed that the health care providers did not provide the women with pre-treatment information on the side effects of either the chemotherapy or the radiotherapy that they received. Mera shared her frustration:

> *"Oh they did not tell me anything at all. This treatment can cause you a lot of troubles so they have to tell us everything before we start so that we know all the things that will happen as I experienced the unexpected"*. **Mera**

Merae who had a similar experience reported:

> *"No, they did not tell me, they should have told me. If something will happen to me as part of the treatment, which may be a bad thing if they tell me I will not be worried when the thing starts. But they didn't tell me so every day I will be thinking of what will happen to me"*. **Merae**

Some of the women admitted they were pre-informed about the side effects of the treatment. However, there was no full disclosure from the care providers. A participant who had partial information from the healthcare providers said:

> *"You see when my skin changed after the radiotherapy, I first thought I was having another cancer. I became even more afraid when I had those things like small, small boils or blisters in my vagina and anus after the treatment. I thought I was getting another deadly disease. So you see, they have to tell us all side effects before we start the treatment"*. **Merac**

Another participant also shared her concern on the partial information she received on the side effects. She was only informed about hair loss but not the weakness as expressed below:

> *"They told me about the hair loss but did not tell me how I will be weak. They also did not tell me about the other side effects, it was when I was experiencing them and complained that they told me that it was due to the treatment Oh! if they had told me, it would have helped, at least I would have known what to experience so that when the changes were happening I would not be afraid, it would not have been strange to me. But in the case where they did not tell me anything, I thought I was going to die. They should have told me everything from the beginning so that I will know what will happen, In this case I was not free at all because I was thinking about what will happen the next day when I come for treatment"*. **Merad**

The survivors reported that the healthcare providers were not giving them information on the disease they were suffering from and whenever they asked questions they were either not told anything or in some cases were given scanty information.

> *"They have not explained anything to me. They just made me know its cancer. But to say the doctors and nurses have explained my condition to me into details, no, they did not do it. They didn't tell me what has caused my disease. I don't like it at all. The disease is on my body but I don't know anything about it. So they have to tell me everything about the disease, they should not keep it away from me. When I ask them questions they don't want to tell me"*. **Merae**

As the women were not given information on the disease, the women expressed future concerns about their health. For instance, a participant wished to know from the healthcare providers if she will be able to have sex after her treatment however she did not know who to ask. She bemoaned:

> *"The question that bothers me is that, I have seen that the bleeding and the discharge have stopped. After the treatment, when I go back home, can I have sex with my husband? I have been thinking about it. I have not asked anybody, this question has been bothering me, this has been*

> *on my mind, I planned to ask after the treatment but I don't even know who"*. **Merab**

It became obvious that the women lacked knowledge about the presenting signs of cervical cancer hence could not link the symptoms they experienced to the disease. The succeeding quotes depict the women's lack of knowledge:

> *"Till now I don't know what causes the disease and where it came from. Where at all does this disease come from? In fact I didn't know what was happening".* **Mera**

> *"To say the truth I didn't know that this disease can affect the cervix too, cancer? madam what type of disease is this that is affecting women as I had no knowledge about the disease the bleeding and the discharge were flowing I was just at home looking at things I never knew I don't know and I have not heard it before until I came here for treatment".* **Meran**

The lack of knowledge expressed by the women indicated their insatiable quest to know about the disease. The women demonstrated their '*wish*' to know about cervical cancer:

> *"What actually causes the disease I don't know 'I wish I know what has caused the disease am suffering from'. I feel they should find whatever is causing the disease so that if one knows the cause you will know how to manage yourself. For example, if they tell me it is because I have eaten a kind of food that has caused the disease then I will know what to eat and what not to eat"*. **Merac**

It became obvious that the inability of the healthcare providers to provide information to the women made some of the participants perceive that the healthcare providers themselves do not know or have adequate knowledge about the disease. The perception of the women were embedded in the following quotes:

> *"Yes, I can also see that, may be some of the doctors and nurses at all those hospitals I have been going to do not know about this disease so when they see the signs they don't know"*. **Meraf**

> *"As for me what I have seen or can say is that, it looks as if the health workers also don't know about this disease. You see when the thing was happening like that I went to*

> *hospitals and narrated all that was happening to me like the discharge but they could not tell me anything. Somebody must teach them [health workers] they don't know they don't sister. They have to teach them".* **Merak**

4.7.1.2 Delays

The women in their narrations indicated their concerns about the delays they experienced as they seek healthcare. The women stated that, during their initial encounter with the healthcare setting, they had to wait for a long time before receiving their initial laboratory results. Meral and Merao shared their concerns:

> *"I waited for over one month before I had the result. So after two months they called me that the result is in so I should come and when I went they said it was cervical cancer".* **Meral**

> *"It was not easy when I was waiting for the results. I didn't know why the result took that long, all the times I went to the hospital to do test, they didn't take that long to tell me the result, at most two days then I will get the result, but this one it took so much time. When the result was delaying I was asking myself what is wrong".* **Merao**

Another form of delay expressed by the women was that they attended several hospitals before they were finally diagnosed of cervical cancer. Some women had these comments to make:

> *"I went to several hospitals. It was at the ninth hospital that they told me that it was cervical cancer".* **Meraf**

> *"I went to the hospital several times but they didn't know what the exact problem was. As for the hospitals, I cannot count, they were so many".* **Merai**

The women complained about the postponement of their clinic schedules mainly by the doctors which further delayed their diagnoses. Merad, Meraf and Meraj expressed their experiences in the following quotes respectively:

> *"I don't understand why they keep postponing the test. I was not happy, you have to go and come, go and come by the time they diagnose the disease has advanced"*. **Merad**

> *"The doctor said I should go and come, go and come and I will come and wait and wait, every time I was thinking what the problem was"*. **Meraf**

> *"Come today, come tomorrow! They said I should go here, go there. So I said what is going on, the go and come was too much"*. **Meraj**

4.7.1.3 Misdiagnosis

Some of the women were misdiagnosed by a doctor at a point in time of the referral process. Some of the women were diagnosed as being '*pregnant'* while others were told that they had '*fibroids'.* Two women confessed that:

> *"They asked me to do a scan and I did. The doctor saw the result and said I was pregnant and I told him I was not pregnant. Ah how can I be pregnant?"* **Merac**

> *"They said it was fibroid so they did an operation for me but when I demanded that I wanted to see the fibroid they didn't show me anything"*. **Merai**

Still in line with the misdiagnosis, another woman was told she was about to have her menopause that was why she was experiencing those symptoms. She shared:

> *"They said for a woman if you are about to have your menopause you will experience things bleeding. They were not able to tell me the truth as to what was wrong with me".* **Meraf**

4.7.1.4 Negative Health Personnel Attitude

Some of the women reported on attitudes of the health care providers that could be termed as negative. The women were not pleased with the manner in which the doctors broke the news of their diagnoses to them. Meraf shared her encounter with a doctor:

> *"The doctor didn't tell me that it was cancer, he told me 'how did you allow yourself to have this sickness?' he did not tell me that it was cancer".* **Meraf**

Another woman with as similar concern had this to say:

> *"The doctor told me cancer does not have any end, if they treat it today it can go to another part of the body. I cried bitterly, I cried, she told me point blank that cancer does not have any end. Whether it is done or not it can run to another place and you can die. I wept in front of her so she asked me why I was crying and I said aah, aah, all these series of problem I have been through, if I knew that by all means I will die I should have just stayed and died, why do I have to go through problems and then die?*" **Merag**

Another woman expected to be informed of her diagnosis in a '*sympathetic manner'* but it was done in a way that made her '*terrified*' and she cried. These were her words:

> *"I was expecting her to tell me in a sympathetic manner. Suddenly I was terrified remembering that my sister died from the same thing. I even cried because it was a very difficult moment for me. Thank God, one of my daughters was with me so she comforted me telling not to worry that they will support me to get healed. I felt very sad, I even cried"*. **Merad**

The same woman was not pleased with the attitude of the radiotherapy staff. They were jumping the queue instead of calling patients in an orderly manner. This gave her the perception that the workers were taking bribes from the patients.

> *"The problem is at the machine room. They don't call people according to the way we came. Sometimes you will be there before somebody will come but they will attend to the person before you. I think the patients have been "pushing" some small money to them in order to cross the line. You will sit here before somebody will come, they will pretend as if they are going to book them, then they put them in the machine. When it happens like that, you that woke up early and came for treatment will end up leaving the place late in the afternoon"*. **Merad**

In summary, women's experiences as they accessed health care varied from inadequate information, delays, misdiagnosis and personnel attitude. It was evident in the findings that the women expressed their dissatisfaction with these concerns. These issues could affect the well-being of the women.

4.8 Summary of Findings

This chapter analysed 15 interviews conducted among women surviving cervical cancer in the Accra metropolis. Five major themes were derived. Four of these themes (physical well-being of women with cervical cancer; psychological well-being of women with cervical cancer; social well-being of women with cervical cancer; and spiritual and coping strategies of women with cervical cancer) were consistent with the Ferrell et al. (1999) QoL model used as an organizing framework. However, the fifth theme, health system factors was not consistent with the QoL model but emerged from the data.

The women surviving cervical cancer had varied experiences in line with these themes and the model. The emerging concerns or sub-themes of the women were in the physical domain, which were solely disease and treatment related, namely: pain; gynaecological problems; gastrointestinal disturbances; disfigurement; impaired functional activities; and impaired rest and sleep. It became obvious from the data that the survivors had a poor physical well-being.

The psychological well-being of the survivors was explored in line with the following subthemes: anxiety; depression and suicidal tendencies; cognition/attention; distress of diagnosis; and grieving and fear of death. It was evident that the physical experiences of the survivors have a tremendous effect on their psychological well-being. In entirety, the survivors of cervical cancer in this study had a poor psychological well-being.

Again, the social well-being theme had sub-themes, namely: impaired relationships; social isolation; economic burden; and support networks. The survivors had marital relational problems. Social isolation was a major finding in the survival experiences of the women as well as economic burden. Most of the women had a formidable support network as they survive cervical cancer whereas others did not. Generally the survivors had poor social well-being.

The spiritual well-being and coping strategies of women with cervical cancer had these subthemes: meaning of illness and acceptance; a sense of hope and religiosity; uncertainty; and the will to live. Survivors of cervical cancer found diverse meaning from their illness experience. Furthermore, the women had hope of being healed. However, the women had uncertainties about their future. The survivors generally had a good spiritual well-being.

Health system factors emerged with four sub-themes, namely: inadequate information; delays; misdiagnosis; and negative personnel attitude. The sub-themes illumined the experiences of the survivors as they accessed health care. These factors could affect the well-being of the survivors. In the next chapter, the findings will be discussed in relation to the wider literature.

CHAPTER FIVE

DISCUSSION OF FINDINGS

This chapter presents the discussion of the findings with related literature. The demographic characteristics are discussed first followed by the main themes.

5.1 Demographic Characteristics

The age distribution of the women interviewed ranged from 33 to 67 years with most of the survivors in the age range of 33-45 years. This gives an indication that cervical cancer afflicts women at a time (midlife) when their lives are key to the social and economic stability of their families (Anorlu, 2008; Eze et al., 2013). This finding however disagrees with the age range cited in the study of Issah et al. (2011) where most of the participants were between 51-60 years.

Several risk factors were identified from the study. The study revealed that most of the women had their first sexual encounter between the ages of 13 and 15 years. Most of the women in the present study have had between 5 and 7 sexual partners with the majority reporting remarriages. Furthermore, it was revealed that the women had partners who had had multiple sexual partners. Other researchers reported similar views of these risk factors contributing to the development of cervical cancer among women (Ago et al., 2013; Anorlu, 2008; Eze et al., 2013; WHO, 2015). Even though most cervical cancer cases have been linked to the HPV (type 16 and 18) which is sexually transmitted (Eze et al., 2013; Malik, 2005; Okolo et al., 2010; WHO, 2015), in this present study testing for HPV was not done. However, Okolo et al. (2010) and WHO (2015) reported that HPV type 16 and 18 are responsible for 70% to 78% of cervical cancer cases. Basically, early sexual intercourse, remarriage, multiple sexual partners and having sexual partners who have or had multiple sexual partners may possibly have increased the exposure of the women in this study to the HPV virus. This assertion is congruent with other reports which acknowledged that early sexual intercourse and a history of multiple sexual partners predispose women to HPV (Ago et al., 2013; Eze et al., 2013; WHO, 2015).

Cervical cancer has been tagged as a disease of poverty and of poor women (Denny, 2005; Eze et al., 2012). This statement supports the findings from the present study in which most of the women were petty traders and farmers with possible low income levels which might have contributed to their condition. The level of literacy tends to influence health and health seeking behaviours and low or no literacy leads to poor health (Lindau et al., 2002). A key finding from this study was that the majority of the participants had low educational levels which could have accounted for the women developing cervical cancer. The findings concur with that of Eze et al. (2012) in Nigeria and Thulaseedharan et al. (2012) in India who reported low literacy levels contributing towards poor cervical cancer screening. In view of the above findings, it is important to note that women's knowledge is implicated in cervical cancer screening uptake. Women with low levels of knowledge about cervical cancer and its prevention are unlikely to access screening services (Abotchie et al., 2009; Liao, Wang, Lin, Hsieh, & Sung, 2006) . Most of the women in this study used birth control pills for more than five years which might have predisposed them to the development of cervical cancer. This is in line with ACS (2015) which cited the oral contraceptive usage as a predisposing factor to cervical cancer development. Most of the women in this study had three or more full-term pregnancies which might have predisposed them to cervical cancer. However, none of the participants in the current study has ever smoked. The themes generated in this study are subsequently discussed.

5.2 Physical Well-Being of Women with Cervical Cancer

Women surviving cervical cancer may have good, moderate or poor physical well-being. The findings of the study show that all the participants had poor physical well-being. The poor physical well-being experienced commonly manifested by most of the women were pain, vaginal discharge and vaginal bleeding. Other studies reported poor physical well-being among cervical cancer survivors (Kamau et al., 2007); gynaecological cancer patients (Guo et al., 2004) and cancer patients (Masika et al., 2012). The study further revealed that all the women were in the advanced stages of cervical cancer. The advanced nature as well as the treatment received may be contributory factors to their poor physical well-being. Again, this reiterates the findings of other studies that related to poor physical well-being at the advanced stages of the disease (Nkyekyer, 2000; Vaz et al., 2007) and the treatment received (Bjelic-Radisic et al., 2012).

Cancer pain has been widely reported by a number of studies (Murray et al., 2003; Sepulveda et al., 2003). This study showed that all the women experienced pain as one of the key physical challenges of advanced cervical cancer. Similar findings were reported by other studies. For instance, pain was acknowledged as a problematic physical symptom of advanced cervical cancer (Maree et al., 2013; Reis et al., 2010; Van Schalkwyk et al., 2008; Wainer et al., 2012). Additionally, findings from this study further showed that the women experienced severe pain at different locations of their bodies such as the lower abdomen, leg, and back as well as it being painful to urinate. This finding corroborates with that of other studies which reported that women surviving cervical cancer experience lower abdominal pain (Maree et al., 2014; Wainer et al., 2012) severe leg and back pain (Ago et al., 2013; Maree et al., 2014; WHO, 2006) and bladder pain (Wainer et al., 2012). WHO (2006) cited severe back pain as a sign of late cancer presentation which may likely be the case of the women in the current study as they were diagnosed at the advanced stage. The severe pain may be as a result of tissue damage from the cancer (Levy et al., 2008; Portenoy, 2011) and bone metastases (Thanappprasr et al., 2010).

Impaired sleep patterns among survivors was found in this study. A number of studies have also reported sleep disturbance among cancer patients (Gibbins et al., 2009; Palesh et al., 2010; Parker, Bliwise, & Ribeiro, 2008; Stepanski et al., 2009). The women attributed their sleep disruptions to the pain experienced. This finding is congruent to that of other studies which reported pain as a key cause of sleep pattern disturbance in cancer patients (Furlani & Ceolim, 2006; Mystakidou et al., 2007) and cervical cancer survivors specifically (Maree et al., 2014; Nuhu et al., 2009).

Gynaecological consequences such as vaginal bleeding, vaginal discharge, vaginal dryness, infertility and pseudo-menopausal changes were reported by the women interviewed in this study. The women bled heavily with clots. The vaginal bleeding was spontaneous, post coital, post-menopausal, and irregular menstrual bleeding. These findings are consistent with the varied bleeding patterns cited in other studies such as gynaecological cancers (Wainer et al., 2012) and advanced cervical cancer (Ago et al., 2013; Eze et al., 2013; Langley & Mary, 2012; Maree et al., 2013; VanSchakwyk et al., 2008). The findings on the bleeding pattern described in this current study provides a basis for comparison or contradiction which was argued as lacking in the study of Maree and team in South Africa. In that study, Maree and colleagues claimed that they could not find a study with such a bleeding trend to draw a similarity or otherwise with their study (Maree et al., 2014). The vaginal bleeding experienced by the women led to anaemia that required blood transfusion which was a similar finding among advanced cervical cancer patients in the study of Maree et al. (2014) in South Africa.

Again, the women were in the advanced stages of the disease and reported profuse vaginal discharge as one of the chief symptoms in this study. For instance one of the women described her vaginal discharge as "*a dead rotten animal"* (Merab, p79). This revelation is in line with the findings of other studies which also reported offensive vaginal discharge as a major issue among advanced cervical cancer patients (Ago et al., 2013; Ikechebelu et al., 2010; Langley & Mary, 2012; Oguntayo et al., 2011; Umezulike et al., 2007; Van Schalkwyk et al., 2008). The vaginal bleeding may be due to ulceration of the growth. Whereas the offensive vaginal discharges may possibly be as a result of necrosis and/or infection of the necrotic tissue. This possibly may be the case in the present study.

Another gynaecological finding among the survivors who received radiotherapy in this study was vaginal dryness. The women reported that after receiving some cycles of radiotherapy they experienced poor lubrication in their vagina. This finding may be as a result of the effect of the pelvic radiation which might have caused anatomical and physiological alterations around the pelvic region of the women. This view supports the position of Frumovitz et al. (2005) and Donovan et al. (2007) who reported that vaginal dryness is common among cervical irradiated cancer survivors which resulted from anatomical and physiological changes. Infertility and pseudo-menopausal changes was an outcome of the study. The findings showed that survivors in their childbearing ages experienced menopausal symptoms such as body temperature fluctuations and premature cessation of their menstrual flow. For instance, one of the women in her reproductive age had no child yet her womb was removed as part of the treatment. Findings in relation to infertility and menopausal changes showed that women who had no biological children or wished to have more children were concerned that their treatment induced infertility. Some survivors who have completed their childbearing functions intimated that they had no issues with the loss of their womb except those who equated the womb with femininity. In this regard, Ashing-Giwa (2006) and Reis et al. (2010) were of parallel views that women who link the womb to femininity have concerns about its loss.

Regarding gastrointestinal disturbances, the findings of this study ascertained that women surviving cervical cancer experienced nausea and vomiting, diarrhoea and loss of appetite as side effects of the chemotherapy and the radiotherapy they received and these experiences had a weighty impact on their quality of life. Reports from related studies also showed that patients receiving cancer treatment experience side effects such as nausea, vomiting, diarrhoea, anorexia and fatigue (Akyuz et al., 2008; Distefano et al., 2008; Karakoc & Yurtsever, 2010; Perwitasari et al., 2011; Zeng et al., 2011). The present study found nausea and vomiting as undesirable side effect of chemotherapy which resulted in loss of appetite and weakness. This finding confirms that of Bergkvista and Wengstrom (2006) who found that nausea and vomiting greatly affected the routine activities of women with varied cancers who received chemotherapy. In the same work, survivors reported among other things poor food intake, weight loss, less social interactions and altered sleeping patterns. Consequently, chronic nausea and vomiting made the cancer patients feel tiredness for days after chemotherapy.

Additionally, this study identified diarrhoea as a side effect of chemotherapy and radiotherapy. It was reported that diarrhoea commenced after a few cycles of chemotherapy and lasted for a number of days. The women experienced bodily weakness as a result of the continuous severe diarrhoea. Numerous studies have also reported diarrhoea during chemotherapy (Arbuckle et al., 2000; Benson et al., 2004). Fluid and electrolyte losses can result from severe and persistent diarrhoea consequently causing potentially life-threatening dehydration, electrolyte imbalances, and renal insufficiency (Arnold et al., 2005; Benson et al., 2004; Maroun et al., 2007; Sharma et al., 2005). The treatment-induced diarrhoea experienced by women in the present study might have had a negative effect on their quality of life as reported by other researchers (Arnold et al., 2005; Benson et al., 2004; Maroun et al., 2007; Sharma et al., 2005).

Studies have reported altered eating patterns among survivors of advanced stage cancer (Bell et al., 2009; Hopkinson, 2006). Nutritional symptoms such as anorexia and dysphagia prevent cancer patients from eating adequately (Kubrak et al., 2010). Poole and Froggatt (2002) reported that loss of appetite is a sign of progressive disease among the cancer population, as well as the outcome of toxic cancer therapies. This phenomenon was evident in the present study. The women reported loss of appetite from advance disease and treatment. Chemotherapy and radiotherapy affected the sense of smell and taste of the women and further caused a sore mouth which hindered their ability to eat. This is supported by the views of Kubrak et al. (2010) who reported in their study that dysphagia was a side effect of radiotherapy resulting from throat burns that affected patients' ability to eat. Survivors in this study also had hair loss, skin changes and weight loss as side effects of cancer treatment.

In summary, the physical well-being of the women in this study is generally poor which may affect their quality of life negatively.

5.3 Psychological Well-Being of Women with Cervical Cancer

This theme assessed the state of mind, and the ability to share feelings among the women surviving cervical cancer. Anxiety among cancer patients has been reported in a number of studies and linked to factors such as fear of death (Nuhu et al., 2008), low education and no private insurance (Sharp et al., 2013). Findings from the current study showed that survivors experienced anxiety due to pain. A similar finding was reported in a study in Nigeria. In that study 210 patients with different cancer types including cervical cancer were studied. The investigators reported that the majority of the participants who had pain were more anxious as compared to those who had no pain (Nuhu et al., 2008). The anxiety resulting from pain in the present study may be due to the fact that the pain experienced was severe. Apart from pain, vaginal bleeding and vaginal discharge also made the women anxious. Similarly in the study of Syse and Kravdal (2007), cervical cancer survivors were found to be anxious as a result of the vaginal bleeding they experienced. Vaginal bleeding being a cause of anxiety among cervical cancer survivors could be because the bleeding was severe and unexpected. Anxiety and depression have been noted to co-exist among cervical cancer patients (Yang et al., 2014). Although the co-existence of anxiety and depression was not explored among the survivors in this study, it is highly possible among women in the current study.

Again, the present study found depression in the women surviving cervical cancer. The findings further revealed that depression among the women was multi-factorial. Vaginal bleeding, weight loss, skin changes, loss of fertility and unavailability of funds for treatment were the main sources of depression. The weight loss and skin changes that resulted from the disease process and/or from the treatment altered the physical outlook of the women. They looked entirely different from their pre-cancer diagnosis and treatment appearance which cause depression. This change in appearance may have a resultant negative impact on the quality of life of the women. These findings confirm that of Arunchalam et al. (2011) who asserted that living in a disfigured body, which is visibly different due to cancer or its treatment or due to side effects, lead to depression and poor quality of life. Sharp et al. (2013) also noted in their study that lower economic status at diagnosis is associated with the risk of depression. This revelation is in line with the finding of the current study. The women in this study also became depressed because of the financial constraints they faced in meeting the financial demands of their treatment and cost of living.

Another finding in this study was suicidal tendencies. The suicidal tendencies in this study were as a result of unrelieved pain, dependency and divorce. The women described their pain as severe and continuous, which was likened to labour pain in some instances. Others thought the pain was more severe than labour pain while some could not find appropriate words to describe their pain experience. Pain management strategies failed in alleviating the pain hence the women expressed the desire to die. The association between pain and suicide have further been buttressed in other researches. For instance, Nuhu et al. (2008) and Recklitis et al. (2006) alluded in their respective studies that uncontrolled pain is a contributing factor to suicide among cervical cancer survivors and cancer patients in general. Moreover, an association between pain and suicide was extended to include depression. According to Nuhu et al. (2008), a depressed person is probable to be helpless and hopeless and therefore considers death as an ultimate option to end their 'problems'. This could be the case in the present study. Dependency on others and divorce was discovered in this study to be reasons the women contemplated suicide. Dependency and the sense of burdening others was cited as reasons for some patients to commit suicide (Shime & Hahm, 2011). Divorce as a catalyst to the desire to commit suicide supports the findings of Mystakidou et al. (2006) and O'Mahony et al. (2005) where it was reported that single status is associated with the desire to commit suicide. Body disfigurement such as weight loss and skin changes caused depression among the survivors in the study, which is in support of the findings of Arunchalam et al. (2011) who also linked body disfigurement to depression. Survivors in the current study had depression as a result of vaginal bleeding. Although it appears that no previous study was found to either support or contradict this finding, one may rely on the findings of Nuhu et al. (2008) who linked symptom burden of cancer to depression.

5.4 Social Well-Being of Women with Cervical Cancer

The theme focused on understanding the social well-being of women with cervical cancer as it relates to disease related symptoms and the treatment consequences. Findings from the current study showed that symptoms such as vaginal bleeding, offensive vaginal discharge, pain and vaginal dryness that the survivors experienced affected their ability to have sexual intercourse with their partners. Partly, this finding is in line with that of Maree et al. (2013) in South Africa who noted that vaginal discharge, vaginal bleeding and pain are key symptoms of cervical cancer that prevented the cervical cancer survivors from indulging in sexual intercourse. Furthermore, the current study showed that vaginal dryness as a treatment side effect of radiotherapy affected the sexual activity of the women. This finding shares comparable views with other studies which cited vaginal dryness as a major cause of impaired sexual life of women with gynaecological cancers (Amsterdam et al., 2006; Liavaag et al., 2008; Lindau et al., 2007) and among cervical cancer survivors (Frumovitz et al., 2005; Jensen et al., 2004; Tanjitgamol et al., 2008). The disease related symptoms of cervical cancer and the treatment side effects such as vaginal dryness (poor vaginal lubrication) obviously made the women in the current study lose their desire for sex. Another reason that may be responsible for the avoidance of sexual intercourse among the survivors in the present study could be the combination of anxiety and depression which is embedded in the study of Nuhu et al. (2008) who stated that anxiety and depression has the tendency to decrease sexual functioning among cancer patients. Furthermore, findings of the present study showed that some of the women experienced ineffective communication between them and their partners which affected their marital relationships as partners did not get close to them to even chat. This is in line with the findings of De Groot et al. (2007) who reported that lack of communication and intimacy has the propensity of causing dissatisfaction within a relationship.

Another finding in the current study was that some of the survivors avoided sex because they had the impression that indulging in sexual intercourse will render their cancer treatment unsuccessful thereby worsening their condition. Findings of the present study support that of other studies among cervical cancer survivors. Ashing-Giwa et al.

(2004) and Zeng et al. (2011) established in their studies that cervical cancer survivors avoided sexual intercourse which they believed will worsen their condition and also make the treatment ineffective. Some of the women’s partners forced them to have sexual intercourse against their wishes which the women allowed in order to prevent their partners from seeking sexual pleasure elsewhere and to maintain their relationships. Evidence of this was seen in the studies of O’Sullivan et al. (2006) and that of Afiyanti and Milanti (2013) as a support to the current study. O’Sullivan and his colleague stated in their work that men consider regular sex as a sign of good health and will expect their women to give in to their sexual demands even if the women were sick or too tired to have sex. This may be the reason why some men force their partners to have sex. According to Afiyanti and Milanti (2013), cervical cancer survivors allowed their partners to have sex with them in order to maintain their relationships. This suggests that issues of sexuality and intimacy play a crucial role in the relationships of survivors of cervical cancer. In one instance, divorce after diagnosis was recorded in this study. A similar observation was made in the Wenzel et al. (2005) study in which four survivors attributed their divorce to the diagnosis of cervical cancer. Findings of the current study further showed that the survivor who divorced after diagnosis had a pre-existing problem of childlessness. Comparably, Hacaoglu et al. (2007) found that a problematic relationship prior to cancer diagnosis is likely to have negative consequences after diagnosis. The divorce of this survivor was precipitated by the fact that she had had a hysterectomy as part of her treatment which implied that she will not be able to bear her own biological child. Thus, this is consistent with other studies that cited infertility as a reason for divorce in some western countries (Behboodi-Mogahadam et al., 2013; Obeidat et al., 2014), and within the African society (Dyer et al. 2005; Hollos & Larsen, 2008). Contrary to the relational problems survivors encountered with their partners, this study further established that some of the survivors had no problem with their partners although they could not fulfil their sexual obligations as women. This observation may be as a result of the fact that prior to the survivors' diagnosis of cervical cancer, there was a cordial relationship. This is in support of the findings of Hacaoglu et al. (2007) who reported that a good relationship before cancer diagnosis is likely to be maintained in that good state even after diagnosis.

Even though the family of the survivors were not part of the present study, the survivors reported that their family members experienced great distress due to their cancer diagnosis. Children and husbands were worried and feared the death of the survivors. For instance, children had their individual lives affected as they took up the roles of their mothers (survivors) which at times resulted in anger. Akyuz et al. (2008) in their study of gynaecological cancer women and their partners cited a similar finding that partners of the survivors had emotional difficulties such as fear. To reinforce the distress of children in the present study, reference can be made to the study of Kennedy et al. (2009). In that enquiry, children were said to have been distressed and worried as a result of the diagnosis of their parents. Consequently, the social activities and responsibilities of the children were altered. De Groot et al. (2005) and Hodgkinson et al. (2007) emphasized that gynaecological cancer does not only affect the patient but also the immediate family (partners, children and relatives) which results in stress-related agitation among others. Based on these findings, it may be suggested that care for survivors of gynaecological cancers in Ghana should take a holistic approach to involve the family of survivors.

In addition to the above, social isolation was found in the present study to affect the social well-being of cervical cancer survivors negatively. In this study, social isolation stemmed from various sources. Firstly, the body disfigurement such as hair loss, skin changes and weight loss as a treatment side effect caused visible changes in appearance and body image, which made the survivors alienate themselves from social gatherings. The current study shared comparable views with a previous study by Arunchalam et al. (2011) in which it was stated that visible side effects of cancer treatment causes social maladjustment and poor social interactions which may affect their quality of life. Secondly, disease related symptoms such as offensive vaginal discharge and vaginal bleeding also influenced the social isolation of the survivors. The current study reiterates the findings of Maree et al. (2013) and Van Schalkwyk et al. (2008) who also reported that offensive vaginal discharge and vaginal bleeding among cervical cancer survivors resulted in social isolation. These social isolation concerns of the survivors may mean that they were simply not involved in leisure activities, which possibly may affect their social well-being and quality of life.

The high cost of treatment of cancer (Sharp et al., 2013), and specifically gynaecological cancer has been established (Wainer et al., 2012). A number of studies among cervical cancer survivors cited financial constraints as a major problem (Kamau et al., 2007; Krikeli et al., 2011; Pasek et al., 2012). Lynos and Shelton (2004) stated that due to financial constraints, cervical cancer patients are unable to pay for their cost of treatment. Survivors in this study also expressed related views in terms of high cost of treatment and financial constraints. Findings were that some survivors had to borrow or take bank loans in order to meet their treatment needs. Furthermore, findings showed that financial concerns of survivors have gone beyond cost of treatment (chemotherapy, radiotherapy and laboratory investigations) to include living expenses (transportation, feeding, accommodation) as most of the survivors moved to the city (Accra) to seek treatment. This supports the findings of Wainer et al. (2012) in their study of gynaecological cancers in Australia. Survivors in that study had to travel from distant rural areas to the city centre for treatment which made financial commitment in the treatment of cervical cancer extremely high.

The majority of the survivors who were self-employed had their businesses collapse as they used the proceeds to access treatment which further deepened their financial woes. This is analogous to the findings of Nedjat-Haiem et al. (2012) who reported that loss of jobs among cancer survivors causes financial burden. The support network of survivors in this study ranged from spousal, family, workplace and health workers' support. Almost all the survivors who were married enjoyed spousal support ranging from domestic, physical, financial, informational and emotional whereas a few lacked these. However, a few had no financial support from their spouses. This finding is similar to that of Maree et al. (2013) who stated that some cervical cancer survivors enjoyed spousal support while others experienced the contrary.

Again, in the present study, survivors enjoyed great family support from immediate and extended family members. It is important to note that the finding is a reinforcement of that of Ashing-Giwa and associates who also disclosed that cervical cancer survivors received support from immediate and extended family members, mothers, spouses/partners and children (Ashing-Giwa et al., 2004). Moreover, findings showed that survivors in the present study who were in formal employment had varying experiences. Some of the survivors had tremendous workplace support from both supervisors and colleagues. Supervisors paid the hospital bills for some survivors and granted them leave for their treatment. Contrary findings in this study however, showed that some of the survivors had poor support from co-workers and supervisors. One supervisor/manager forced a survivor to resign from her work.

Generally, survivors had support from health workers. The study findings support that of Ashing-Giwa et al. (2004). In that study, some survivors of cervical cancer received work place support while some did not. An instance of resignation from work was also cited in that study. Ashing-Giwa and team also mentioned that survivors had a satisfying relationship with their healthcare providers (Ashing-Giwa et al., 2004).

In summary, most of the survivors enjoyed support from spouses, family, workplace, and health workers which might have had some positive influence on their social well-being just like the cervical cancer survivors in other studies (Kamau et al., 2007; Zeng et al., 2011). However, survivors in this study had other concerns such as marital problems, financial constraints and social isolation that could have a negative impact on their social well-being.

5.6 Spiritual Well-Being and Coping Strategies of Women with Cervical Cancer

This theme explored the spiritual well-being as well as the coping strategies adopted by survivors of cervical cancer. Findings from the present study showed that the survivors placed a diverse meaning on their illness experience. On one hand, survivors now trust God more because of their experience with cervical cancer. This corroborates the findings of Akyuz et al. (2008) among gynaecological cancer survivors in Turkey where it was reported that cervical cancer survivors felt they could die from the disease hence restored their relationship with God. In Hong Kong, gynaecological cancer survivors professed a positive meaning from their cancer experience. The survivors noted that they had become sensitive to others' needs (Molassiotis et al., 2002). In the study of Ashing-Giwa et al. (2004), cervical cancer survivors mentioned giving back to society as a positive impact they had had from their cancer experience. Findings of Ashing-Giwa et al. (2004) and Molassiotis et al. (2002) were reiterated in the present study where survivors had passion to help other people. Additionally, this study found that survivors had become more compassionate towards people. This could be linked to the findings of Zeng et al. (2011) who reported that survivors treasured life more as a result of their experience with cervical cancer. These findings suggest that experiencing cervical cancer may have a positive impact on survivors. On the other hand, the findings also indicate that some survivors in this study felt the devil is responsible for their disease, and that the disease is a punishment for sins committed. Mabena and Moodley (2012) had a similar finding among cervical cancer survivors in South Africa. In that enquiry, survivors stated that cervical cancer was a result of witchcraft. Survivors also viewed the disease as a punishment for the sins they might have committed. Cervical cancer resulting from the activities of the devil in the present study and a previous study could be a belief that in Ghana, evil spirits are responsible for illness. This assertion may be the case as a similar finding was reported in an earlier study in Ghana (Mill, 2001). According to Mill (2001), ghosts, witches, or sorcery are believed to be the causes of illness. In that same work, participants view illness as a punishment for antisocial behaviour (Mill, 2001).

Survivors demonstrated acceptance of the disease as God's plan, which helped them to cope with their cervical cancer experience and stick to treatment schedules for healing. Comparably, Nedjat-Haiem et al. (2012) had a similar finding. Women in Nedjat-Haiem's study indicated acceptance of their cancer condition, which motivated them to stick to their treatment plans. This gives an indication that as cervical cancer survivors come to the state of acceptance of their diagnosis, they aspire to seek healing through adhering to their treatment schedules, which is commendable as cancer treatment requires continuous adherence to treatment plans.

A sense of hope and religiosity was another significant finding in the present study. It was disclosed that survivors had faith and hope that God will heal them and will do that through doctors and nurses. This supports the assertions of Holt et al. (2009), Mabena and Moodley (2012) and Nedjat-Haiem et al. (2012) who noted that God heals either directly or indirectly through doctors and nurses by giving them the ability to heal. This hope helped the survivors to cope in the face of cervical cancer. Regular prayer and religious study are viewed as ways of coping with cancer (Akyuz et al., 2008; Ashing-Giwa et al., 2004, 2006; Hamilton et al., 2011). Similarly, survivors in the present study also prayed on their own or with the help of others, and listened and read the word of God as a way of coping with cervical cancer. Spiritual support from friends and families and the clergy helped the survivors to move through the trajectory of cervical cancer. Studies acknowledged church attendance as a key activity among cancer survivors (Hamilton et al., 2011; Thune-Boyle., 2011). However, in this study, church attendance was not a regular practice among the survivors mainly because of the offensive vaginal discharge, bleeding and possibly the array of body disfigurements as side effects from treatments. For instance, a survivor in the current study could not attend church because her religious faith forbids women who are bleeding from entering the church: this is similar to the findings of Van Schalkwyk et al. (2008) in South Africa where a woman with cervical cancer could not attend church because the doctrines of her faith prohibits such women from the church. This further reiterates the social isolation cervical cancer survivors encountered. The issue of banning women who are bleeding from entering the church in this study also occurred in the study of VanSchalkwyk et al. (2008) in South Africa. These findings could mean that this phenomenon is a common practice in Africa among some religious faiths.

An improvement in survivors' condition was a source of hope in this study. This supports the findings of Mabena and Moodley (2012) where cervical cancer survivors had their hope of being cured increased when they noticed a remission in the symptoms of cervical cancer. Another finding was that survivors who interacted with other survivors whose condition had improved, gave survivors in the current study further hope of their own healing. This emphasises the crucial role of support groups in the management of chronic conditions such as cervical cancer (Mabena & Moodley, 2012).

The will to live or inner strength as a way of coping was found among the survivors of cervical cancer in this study. Findings showed that survivors wanted to live for their children: to live and find meaning made them move on with their condition. Mabena and Moodley (2012) stated the same findings in their study.

In summary, the survivors had various interpretations about their cervical cancer experiences. The survivors accepted their condition and therefore adhered to their treatment schedules. Survivors also employed prayer and other religious activities with the exception of church attendance to cope. They also received spiritual support from their significant others. Great hope in God as a healer was evident. The survivors believed in doctors and nurses as instruments God use in healing. Although the survivors had uncertainties, they had the will to live for their children.

5.7 Health System Factors

This theme explored the service related experiences of the women surviving cervical cancer as they sought health care. The experiences could have an impact on their well-being. A key finding in the present study was that all the women expressed that they had inadequate information about their condition as well as the side effects of the treatment they received from the healthcare providers. The women expressed their wish to have information about their condition and the side effects of the chemotherapy and the radiotherapy they received. The findings further revealed that health workers were hesitant in providing information to the women. The women’s desire for information in this study is in agreement with that of the majority in the study of Jenkins et al. (2001). In that study, the majority of the participants demonstrated their fervent wish to receive more information about their disease and treatment. However the health care providers were reluctant to give of he needed information (Jenkins et al., 2001). According to Husson et al. (2011), a lack of information or low quality information can result in anxiety, and depression. Even though in the present study the impact of lack of information was not explored, it can be inferred that the lack of adequate information on the disease and the side effects of the treatment might have caused anxiety and/or depression in the women.

Another revelation from the study was that the inability of the health care workers to provide information to the participants concerning their disease and the treatment side effects made the participants perceive that the health care personnel themselves lacked information about cervical cancer. Reports from a number of studies revealed that health care providers lack knowledge on cervical cancer (Mwaka et al., 2013; Urasa & Darj, 2011; Van Schalkwyk et al., 2008). Therefore it is speculative that findings on the perceived lack of knowledge of health workers in the present study may be true.

This study also exposed the lack of knowledge of all the participants on the symptoms of cervical cancer. It was obvious that none of the women was able to associate the myriad of symptoms they experienced to cervical cancer. This finding is consistent with that of other studies (Issah et al., 2011; Langley & Mary, 2012; Van Schalkwyk et al., 2008). For instance, Van Schalkwyk et al. (2008) stated unequivocally that women with cervical in their study could not associate the symptoms they experienced to the disease. This implies that more education of the public on the symptoms of cervical cancer is required.

In addition to the above, delay in receiving care was also a key finding in this study. The women had to visit numerous health care delivery points to be diagnosed. This may be so as the women might have spent time attending lower level health care centres in their localities that lacked trained personnel and the specialized equipment required for the diagnosis of cervical cancer. This observation is in line with the findings of Mwaka et al. (2013) and Van Schalkwyk et al. (2008). In the study of Mwaka and associates, it was reported that there were few specialized cancer treatment facilities in the countryside which implied that patients had to travel to the capital to seek treatment. In the same study, it was stated that health workers at the lower health care settings lack adequate knowledge on cervical cancer, which affected their ability to take decisions and also diagnose (Mwaka et al., 2013). The Van Schalkwyk et al. (20008) study in South Africa reported that health workers failed women experiencing signs of cervical cancer as the women had to continually attend the primary healthcare clinics before they were finally diagnosed. Even though the impact of the delay was not explored further in the present study, the delay might have resulted in a form of distress as reported in a number of studies. For instance in the study of Mwaka et al. (2013), it was found that delay in getting cytology/ histology results, losses of biopsy sample led to frustrations and distress among cervical cancer survivors. Similarly, participants in the study of Maree et al. (2014) also registered their displeasure about the delay in their diagnosis.

Misdiagnosis was found to be an element in the current study. Most of the women were misdiagnosed. Similar findings of misdiagnosis were reported in other studies among cervical cancer survivors (Mwaka et al., 2013; Van Schalkwyk et al., 2008) and gynaecological cancer patients (Wainer et al., 2012).

Women in the current study expressed their concerns about the manner in which they were informed about their diagnosis. The findings showed that the women were not pleased with the way the doctors disclosed their diagnosis. Some of the participants expected to be informed of their diagnosis “sympathetically” but this was not done. Even though the effect of the way the women were informed of their diagnosis was not explored further in the present study, it can be inferred that the process of news disclosure might have resulted in psychological distress such as depression and anxiety. Indeed, health system factors such as lack of the provision of adequate information, delays in healthcare delivery, misdiagnosis of survivors, and negative health personnel attitudes have the tendency of impacting on the well-being of survivors of cervical cancer just as the disease symptoms and treatment related concerns.

In conclusion, it is apparent that the survivors in the present study had poor physical well-being resulting from the disease symptoms and treatment related issues. The survivors had pain; gynaecological problems such as offensive vaginal discharge, vaginal bleeding, vaginal dryness; infertility; and pseudo-menopausal changes. Furthermore, the psychological well-being of survivors was negatively affected. It became obvious that the disease symptoms and treatment related effects of social well-being had psychological implications for the survivors in that they experienced anxiety due to pain, vaginal bleeding and vaginal discharge. Depression as a psychological morbidity stemmed from the vaginal discharge, weight loss, and skin changes. Pain, the thought of dependency and divorce were responsible for the suicidal tendencies among some of the survivors in the current study. The survivors grieved and feared death.

Even though the survivors had some support from significant others, they also encountered numerous problems that affected their social well-being. For instance, they had marital problems mainly due to the fact that the survivors could not fulfil their sexual obligations. The immediate family of the survivors also experienced some distress reiterating the stance that gynaecological cancers affect not only the survivor but the family as well. Again, the survivors had social isolation, which was mainly due to body disfigurement from treatment and disease symptoms such as offensive vaginal discharge and vaginal bleeding. As the survivors accessed health care, they encountered economic problems, which took a toll on the survivors and their families in entirety.

Additionally, survivors employed prayers and other religious strategies in coping with their cancer experience. The survivors accepted their cancer disease as coming from God and had hope of being healed through the doctors and nurses. The survivors demonstrated their will to live, an inner strength that encouraged them to move on in the face of cervical cancer. To this end, apart from the disease symptoms and treatment related concerns that affected the well-being of survivors, it became obvious that health system factors mainly related to the health personnel as they deliver health care had the possibility of affecting the psychological well-being of the survivors.

CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS

This chapter focuses on the summary of the study, implications, limitations, conclusions, and recommendations.

6.1 Summary of Study

The study explored the survival experiences of women with cervical cancer in the Accra metropolis using the Quality of Life Model Applied to Cancer Survivors as the organising framework. Collection of data started after ethical approval was sought from the Institutional Review Board Noguchi. Pre-testing of the interview guide was done at the Radiotherapy Centre of the KBTH for clarity of questions. A total of 15 survivors were recruited for the study. Recruitment of participants, interviewing and transcription commenced concurrently from July to November 2014. The participants gave their consent to be part of the study. Each interview was audio taped and transcribed verbatim. Data analysis was done employing the principles of thematic content analysis.

Key findings showed that survivors of cervical cancer experienced disease related symptoms and side effects from the treatment they received. The survivors experienced severe pain in the abdomen, legs and back. Also, survivors had gynaecological problems such as vaginal bleeding, offensive vaginal discharge, vaginal dryness as well as infertility, and pseudo-menopausal changes. Nausea and vomiting, loss of appetite and diarrhoea were gastrointestinal problems the survivors encountered as a result of the radiotherapy and chemotherapy they received. Hair loss, skin changes and weight loss were the common body disfigurements the survivors suffered from. The functional activities of the survivors were impaired as well as their sleep patterns. All these experiences resulted in a poor physical well-being of the survivors.

The disease related symptoms and the treatment side effects affected the psychological well-being of the survivors. The survivors had anxiety because of pain, offensive vaginal discharge and vaginal bleeding. Additionally, weight loss, vaginal bleeding and skin changes made the survivors depressed. Some survivors had suicidal tendencies which were as a result of unrelieved pain, dependence on others and divorce. Distress of the news of diagnosis was demonstrated through anger, shock, disbelief, and denial. Most of the survivors grieved and feared death. It can be inferred that the psychological well-being of the survivors was poor.

Survivors' relationships with their partners/spouses was affected mainly due to the fact that most of the survivors could not fulfil their sexual obligations to their husbands. However, some other survivors tried to maintain their sexual activities amidst the physical consequences from the disease itself and the treatment in order to maintain their relationships and to prevent their partners from seeking sexual pleasure elsewhere. Some survivors willingly asked their spouses to marry other women. It became obvious the individual lives of survivors and that of their families were impacted. Partners and children were stressed.

Social isolation was a key problem for the survivors. The disease symptoms and body disfigurements resulting from the treatment prevented the survivors from socialising. Also, the treatment of cervical cancer was expensive which placed an enormous financial burden on the survivors and their families. The businesses of survivors were disrupted worsening their financial plight.

It was apparent that most of the survivors enjoyed good social support. Most survivors who were married enjoyed spousal support ranging from domestic, financial, and emotional. However, a few of the survivors though married, did not have financial support from their partners. Most of the survivors received tremendous support from the family, workplace and health workers. Although survivors had social support, their social well-being was generally poor.

Survivors attached various meanings to their disease experience such as being sensitive to the needs of others. Some survivors felt that they were bewitched. Furthermore, survivors coped with the disease through acceptance, prayer and having a sense of hope that God will heal them directly or through the doctors and nurses. Survivors also employed other religious activities such as listening to the word of God and reading the bible or the Quran which helped them to cope. They also had the will to live, which was a way of coping. Again, survivors were uncertain about their time of death, work and marriage. In whole, survivors had a good spiritual well-being.

Lastly, the findings showed that some activities of health care professionals as they rendered care to the survivors affected the psychological well-being of the survivors. There were instances where the survivors were not provided with adequate information about their disease or the treatment’s side effects. Survivors also complained of delays and misdiagnosis, which affected them psychologically. Survivors indicated that the way the doctors broke the news of their diagnosis to them made them depressed.

6.2 Implications

The findings of this study brought to light some implications that need to be addressed. These implications are geared towards nursing education, nursing practice, nursing research, and for policy formulation.

6.2.1 For Nursing Education

The findings showed that the survivors perceived that nurses lacked adequate knowledge on the signs and symptoms of cervical cancer; hence, their inability to identify and explain symptoms related issues to survivors. There is, therefore, the need to assess, train and re-train nurses at all levels of health care delivery to aid in the prompt identification and early diagnosis of cervical cancer.

Survivors further stated that there was inadequate information on both the disease (cervical cancer) and the treatment side effects. Nurses need to be reminded of the rights of patients as enshrined in the patients’ charter. These rights include, among others, the rights to know their diagnosis, treatments and side effects of all available treatment options. All these will help in allaying the anxiety of the survivors. The Ministry of Health should also consider building oncology nursing training schools all over the country which will focus on the training of oncology nurses who will have the special knowledge and skills in caring for cancer survivors and their families.

6.2.2 For Nursing Practice

The findings showed that pain as a key symptom of cervical cancer affected various aspects of life of the survivors. This emphasises the multi-dimensional nature of pain. There is the need for nurses to explore both pharmacological and non-pharmacological approaches in managing pain among cervical cancer patients. Nursing care for cervical cancer survivors should take a holistic approach. This is because the findings of this study showed that the family of cervical cancer survivors are also affected as they care for the survivors. Such an all-inclusive approach will ensure the well-being of the caregivers as well.

6.2.3 For Nursing Research

This study showed the need for further research. This present study explored the survival experiences of women with cervical cancer. Future research may explore the experiences of partners of survivors or the couple as a whole. This will help comprehend the phenomenon better than the unilateral views of only the survivors as explored in this study. Again, the experiences of children of survivors of cervical cancer could also be studied. This will bring to the fore what such children go through as they travel through the trajectory of cervical cancer with their mothers.

Again, the psychological experiences of survivors may be explored quantitatively to further understand the psychological experiences of women with cervical cancer.

6.2.4 For Policy Formulation

The findings revealed that cervical cancer survivors face huge financial constraints in accessing health care, which includes the cost of treatment and living expenses. This is mainly because most of the survivors were unable to work due to disease related symptoms and treatment concerns. A policy should therefore be developed to bring about the subsidisation of the entire treatment cost of cervical cancer.

6.3 Limitations

Due to the qualitative approach employed in the study, only few participants were required in order to ensure an in-depth comprehension of the experiences of cervical cancer survivors. To that effect, the findings may not be generalizable. However, transferability may be done when the context is similar. In order to generalize the findings, a quantitative or mixed method approach will be suitable to allow a larger sample size.

6.4 Conclusions

Some of the findings of the study were consistent with the constructs of the Quality of Life Model Applied to cancer survivors (QoL-CS) while other findings emerged from the data. Firstly, the physical well-being of women with cervical cancer represented in the model as physical well-being and symptoms, found the following findings to be congruent with the constructs of the model; pain, impaired functional activities, impaired rest and sleep, infertility and pseudo-menopausal changes, gastrointestinal disturbances, and body disfigurements**.** On the other hand, gynaecological findings such as vaginal bleeding, offensive vaginal discharge, and vaginal dryness were found to be additional factors related to the physical well-being and symptom domain of the model.

Secondly, the psychological well-being of women with cervical cancer captured in the model as psychological well-being also had findings that were either consistent or otherwise with the model. For instance, anxiety, depression, cognition/attention, and distress of diagnosis were identified to be consistent with the model. However, suicidal tendencies, and grieving and fear of death, were other factors reported by the survivors in the present study.

Thirdly, the social well-being of women with cervical cancer represents the social well-being domain of the model. The findings showed that impaired relationships (marital problems and family distress), social isolation and economic burden were in alignment with the constructs of the model. It is important to mention that the affection/sexual function as cited in the model was described under marital problems as part of findings of impaired relationships. Also, appearance and enjoyment as stated in the model is embedded in the findings of social isolation. Additionally, finances and work as in the social well-being domain of the model were captured under the economic burden findings. However, a support network was inconsistent with the constructs of the model.

Fourthly, the spiritual well-being and coping strategies of women with cervical cancer signifies the spiritual well-being of the model. Findings such as meaning of illness, a sense of hope and religiosity, uncertainty and the will to live (inner strength) were consistent with the model but acceptance was inconsistent with the model.

Lastly, health system factors comprising of inadequate information, delays, misdiagnosis, and negative health personnel attitudes were additional concerns reported by the survivors.

Consequently, the findings suggested that the cervical cancer survivors experienced a host of physical consequences from disease related symptoms and treatment side effects. These physical effects impact upon the psychological and social well-being of the survivors in their daily lives which made the women more spiritual in order to cope.

The treatment cost posed a huge financial burden for the survivors and their families. Families of survivors, both immediate and extended were affected in diverse ways. Furthermore, most of the survivors had a history of early sexual encounters, multiple sexual partners, and prolonged use of oral contraceptives. The survivors indicated their lack of knowledge on the presenting signs and symptoms of cervical cancer. Findings from the study again showed that health workers did not provide adequate information to survivors on the disease and the side effects of treatment. There were instances of delays in diagnosis, misdiagnosis and other negative health personnel attitudes. These health system factors had psychological implications for the survivors.

In conclusion, due to the interrelated nature of the cancer experience, there is a need for a multi-disciplinary approach in the management of cancer survivors. There is also the need for a holistic patient/family centred care rather than individualised care of the survivors. Families of survivors should be informed of the essential role their support plays in the survival of women with cervical cancer. Furthermore, awareness creation within the public on the risk factors and presenting symptoms of cervical cancer is necessary. Health workers should have updated knowledge on cervical cancer related issues in order to render a higher quality of care to survivors of cervical cancer in Ghana.

6.5 Recommendation

Based on the findings of this study, some recommendations were made to the Ministry of Health, Ghana Health Service, KBTH (Radiotherapy Centre), women/girls, families of survivors, and the general public.

6.5.1 Ministry of Health (MoH)

The MoH should:

- Train and retrain nurses and physicians on the early signs of cervical cancer.
- Organise regular in-service training for nurses, physicians, pharmacists, clinical psychologists/counsellors and spiritual leaders to enhance their skills in cancer management so as to ensure holistic care of cervical cancer survivors.
- Organise periodic training for nurses and physicians on effective health worker-patient communication.
- Embark on regular nation-wide education of the public on the risk factors, signs and symptoms of cervical cancer and the need for regular screening.
- Lobby government for the inclusion of the treatment cost of women with cervical cancer in the National Health Insurance Scheme as a form of support.

6.5.2 Ghana Health Service (GHS)

The GHS should:

- Establish a well-equipped hospital in each region with experts to aid in early detection and treatment of cancer.
- Adopt a multi-disciplinary care approach in the management of cervical cancer.
- Create awareness on the early signs and symptoms of cervical cancer.
- Make cervical screening services affordable and accessible nation-wide.
- Ensure prompt referral of cervical cancer cases to treatment centres to prevent delays.
- Organise regular refresher courses on the signs and symptoms of cervical cancer for health workers to eliminate cases of misdiagnosis.

6.5.3 KBTH (Radiotherapy Centre)

Staff of KBTH (Radiotherapy Centre) should:

- Make time to provide information to patients about their diagnosis of cancers and the possible side effects of their treatment (chemotherapy and radiation therapy).
- Reward hard working staff charged with the care of cervical cancer survivors periodically.
- Render unbiased care to patients especially those with cervical cancer.

6.5.4 Women/Girls

Women/girls should:

- Be vaccinated against the HPV before their first sexual encounter (those between the ages of 9-13 years).
- Practise regular cervical screening.
- Embrace safe sex practices to decrease their exposure to the HPV.

6.5.5 Families of Patients with Cervical Cancer

- Families of patients with cervical cancer should render an all-round support (emotional, spiritual, financial) to survivors.

6.5.6 General Public

- The general public should show acceptance of people living with cancer and avoid stigmatization and isolation.

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Appendix A: Background Information Form

Code Number……………..

1. Age:
2. Place of residence………………………………………………
3. Nationality …………………………………………………..
4. Marital status: Married[ ]; Divorced [ ]; Never married [ ]; Separated [ ]
5. If married/divorced, is this the first or second marriage?
6. Age of first sexual encounter? …………………………….
7. Number of sexual partners you have had? …………………………….
8. Have you ever had a sexual partner who had multiple sexual partners?
9. Number of children………………………………………………….
10. Occupation …………………………………………………………
11. Level of education …………………………………………………
12. Languages spoken ………………………………………………….
13. Religion …………………………………………………………….
14. How long have you been diagnosed with cervical cancer? ....
15. Are you still receiving treatment? Specify ……………………………………….
16. Do you smoke?...
17. Have you ever used a birth control method?
18. If yes to question 17 above, which type and for how long did you use that method?

Appendix B: Interview Guide

Interview Guide

Research Topic: Surviving Cervical Cancer: Experiences of women in the Accra Metropolis

Researcher: Kafui Abra Hobenu (MPhil. Nursing Student)

Address: School of Nursing University of Ghana

Telephone: 0244740114

The questions were developed according to the objectives of the study to guide the interviews. The participants' response will guide the questions through probing questions. The interview guide will contain lists of open-ended questions which have been derived from the objectives of the study.

SECTION A: Physical well-being of women with cervical cancer

1. Please how did the disease start?

   Probes: Symptoms: Pain, Vaginal bleeding and Discharges

2. Please share with me a typical day of your life after the diagnosis?

   Probe: Sleep, Fatigue, Daily Activities

3. Please what treatment have you been receiving? Tell me more about it.

   Probe: Side effects, Complications

SECTION B: Psychological well-being of women with cervical cancer

4. Please tell me how you felt when you were first told that you have cervical cancer?

   Probe: Shock, believe/disbelieve

5. Please can you share with me anything about this disease that disturbs you?

   Probe: Fear, Anxiety, Mood changes

6. Please share with me how you feel about life entirely?

7. Please at what stage did you decide to seek medical attention? Please explain further.

SECTION C: Social well-being of women with cervical cancer

8. Please how has the disease affected your life?

   Probe: Socialization, Visiting friends/places of interest, Effect on Children/family

9. Please share with me how you have been managing your life after the diagnosis

   Probe: Roles/responsibilities, Work, Marriage/relationships/communication/sexual issues, Financial concerns/cost

10. Please share with me how people relate with you since you were diagnosed?

    Probe: Family, Friends, Co-workers, Neighbours

SECTION D: Spiritual well-being and coping strategies of women with cervical cancer

11. Please what gives you strength to move on in the face of this disease?

    Probe: Spirituality/Religiosity, Hope, Inner strength

12. Please share with me what you think of this disease experience?

    Probe: Source of disease, Meaning of illness, Any impact on personal life

13. Please share with me your concerns about the future?
14. Please share with me any recommendations to help other women in the same situation?
15. Please is there anything else you will like to share with me?

THANK YOU

Appendix C: Information Sheet

TITLE OF STUDY: Surviving cervical cancer: Experiences of women in the Accra Metropolis

Name of Principal Investigator: Kafui Abra Hobenu

Address: School of Nursing, University of Ghana

Tel. Number: 0244 740 114

Email: kelho45@yahoo.co.uk

Dear Participant,

I am a graduate student from the School of Nursing, University of Ghana, Legon and I am carrying out a study and you are invited to participate to understand the survival experiences of women with cervical cancer.

Why am I doing this study?

I would like to seek information from women diagnosed with advanced cervical cancer. I am expecting that when I get information on your experiences, it will help me understand what will help support women with cervical cancer.

What will happen during the study?

I will have a conversation with you and you are free to speak English, “Twi” or “Ewe”. There is no right or wrong answer. You are free to refuse to answer any question that you are uncomfortable with. The duration of the interview will be between 45-90 minutes. The interview will be conducted at a location and time convenient to you. A second interview may take place if necessary. The dialogue will be about the things you have gone through since your cancer diagnosis. You will be asked to sign or thump print a consent form.

Will anyone know what you told me?

I will record the conversation on a tape recorder and later it will be written in words. Your name will not be recorded on the tape or the paper. A number and a false name will be given to your conversation. The only people that will know about our conversation will be my supervisors. Any information that bears your name will be kept under lock and key at a separate place from the written information for 5 years after the study and then discarded.

What are the possible gains and harm to you?

At the moment, the study may not have any direct benefit for you, but I believe the feelings of women who have been diagnosed with cervical cancer will be understood. This will enable health workers to design programmes that will help such women.

It is not anticipated that taking part in this study will be harmful to you but you may feel emotional about telling your story. When that happens, the researcher will refer you to a professional who can talk to you and relieve you of your emotions without any financial cost you.

Can you withdraw from the study?

You are at liberty to leave the study at any time you wish even after you have agreed to be part of the study. Your withdrawal will not affect the health care you are receiving. Also you will not be expected to give reasons for your exit.

Additional Contacts

If you have any concerns you can send an email or phone the researcher of her supervisors using the contact addresses:

Kafui Abra Hobenu: kelho45@yahoo.co.uk Phone number: 0244 740 114

Dr. Lydia Aziato: aziatol@yahoo.com Phone number: 0244 719 686

Dr. Florence Naab: florencenaab@yahoo.com Phone number 0263741717

Thank you

Appendix D: Introductory Letter

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

Telephone: 0302-513255 (Dean)
Ext. 6206
0302-513250 Secretary
028 9531213
Fax: 513255
E-mail: nursing@ug.edu.gh

P. O. Box LG 43
LEGON, GHANA

RECEIVED
Date 4/7/2014
KORLE-BU

Our Ref: SON /F11
Your Ref:

July 3, 2014

The Director
National Centre for Radiotherapy & Nuclear Medicine
Korle-Bu Teaching Hospital

Dear Sir,

INTRODUCTORY LETTER

I write to introduce to you Kafui Abra Hobenu, an M.Phil student of the University of Ghana, School of Nursing. She is seeking your permission to collect data for her research on the topic **"Surviving Cervical Cancer: Experiences of Women in the Accra Metropolis."**

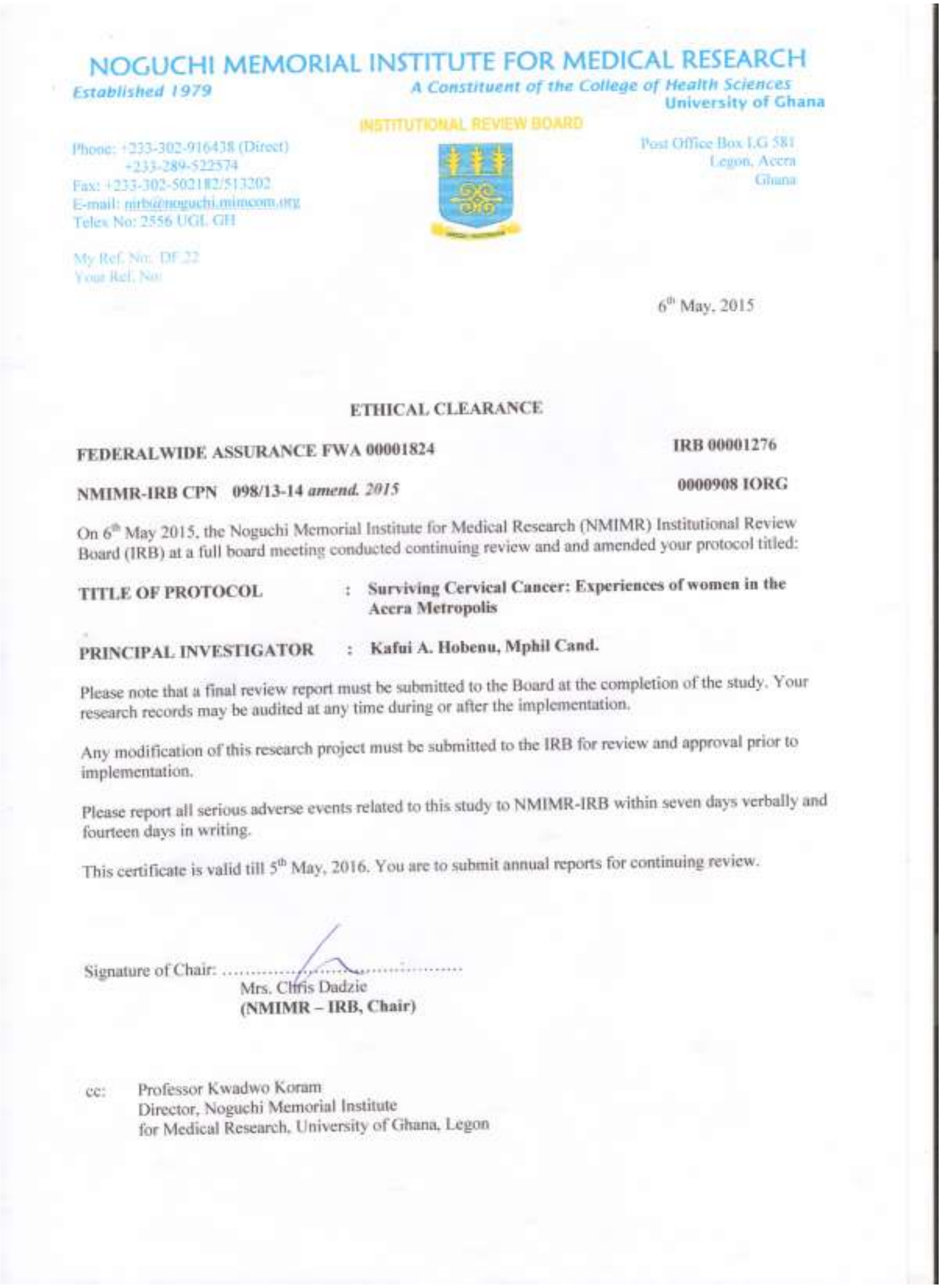
I would be grateful if you could kindly assist her with the information that she may require for her thesis.

Thank you.

Yours faithfully,

Dr. Lydia Aziato
SUPERVISOR

Appendix E: Ethical Clearance Letter



NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Sciences
University of Ghana

INSTITUTIONAL REVIEW BOARD

Phone: +233-302-916438 (Direct)
+233-289-522574
Fax: +233-302-502182/513202
E-mail: nirb@noguchi.mimcom.org
Telex No: 2556 UGL GH

Post Office Box LG 581
Legon, Accra
Ghana

My Ref. No: DF 22
Your Ref. No:

6th May, 2015

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824 **IRB 00001276**

NMIMR-IRB CPN 098/13-14 *amend. 2015* **0000908 IORG**

On 6th May 2015, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting conducted continuing review and and amended your protocol titled:

TITLE OF PROTOCOL : **Surviving Cervical Cancer: Experiences of women in the Accra Metropolis**

PRINCIPAL INVESTIGATOR : **Kafui A. Hobenu, Mphil Cand.**

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

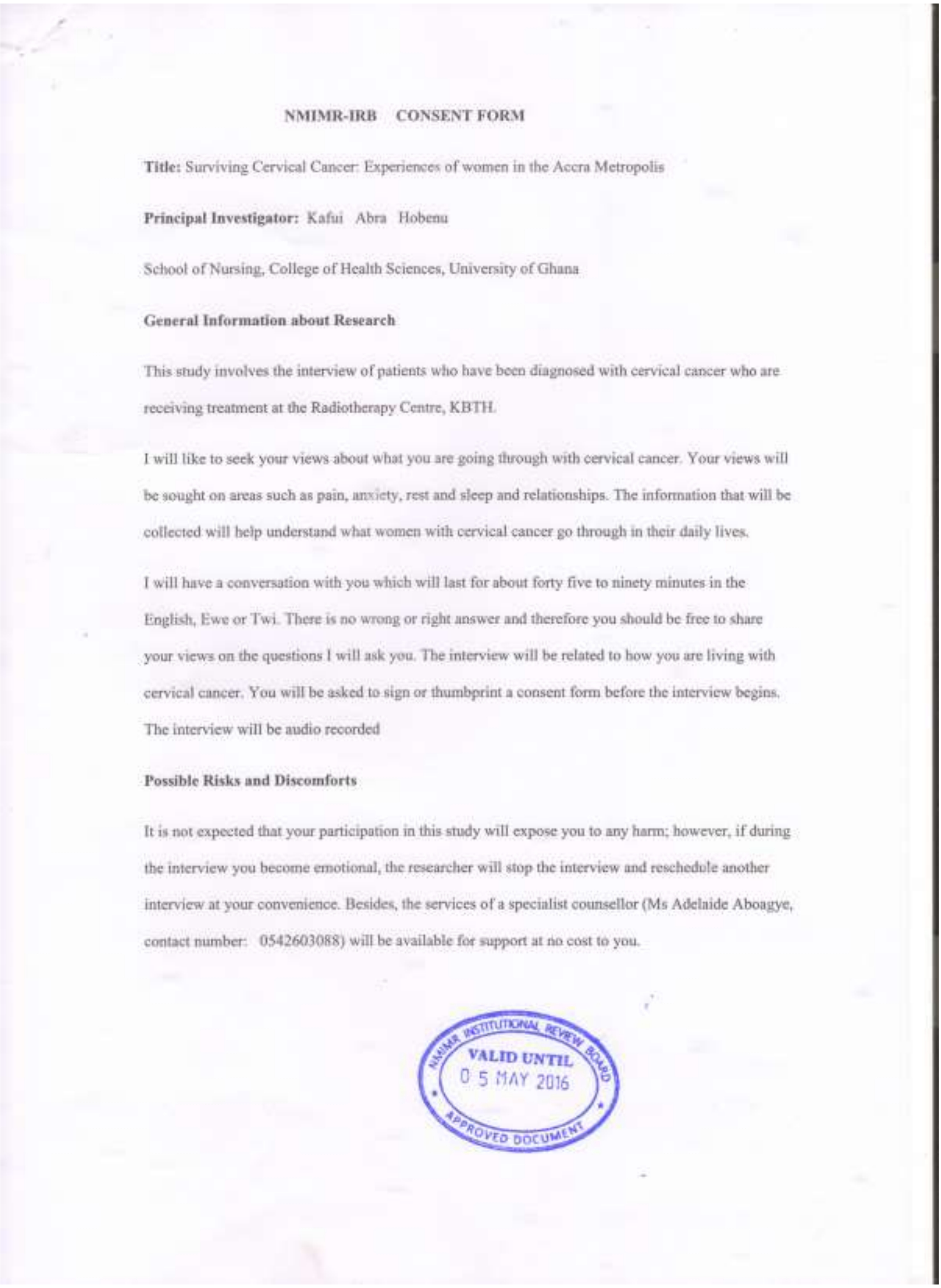
Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 5th May, 2016. You are to submit annual reports for continuing review.

Signature of Chair: ……………………………………………
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)

cc: Professor Kwadwo Koram
Director, Noguchi Memorial Institute
for Medical Research, University of Ghana, Legon

Appendix F: Consent Form



NMIMR-IRB CONSENT FORM

Title: Surviving Cervical Cancer: Experiences of women in the Accra Metropolis

Principal Investigator: Kafui Abra Hobenu

School of Nursing, College of Health Sciences, University of Ghana

General Information about Research

This study involves the interview of patients who have been diagnosed with cervical cancer who are receiving treatment at the Radiotherapy Centre, KBTH.

I will like to seek your views about what you are going through with cervical cancer. Your views will be sought on areas such as pain, anxiety, rest and sleep and relationships. The information that will be collected will help understand what women with cervical cancer go through in their daily lives.

I will have a conversation with you which will last for about forty five to ninety minutes in the English, Ewe or Twi. There is no wrong or right answer and therefore you should be free to share your views on the questions I will ask you. The interview will be related to how you are living with cervical cancer. You will be asked to sign or thumbprint a consent form before the interview begins. The interview will be audio recorded

Possible Risks and Discomforts

It is not expected that your participation in this study will expose you to any harm; however, if during the interview you become emotional, the researcher will stop the interview and reschedule another interview at your convenience. Besides, the services of a specialist counsellor (Ms Adelaide Aboagye, contact number: 0542603088) will be available for support at no cost to you.

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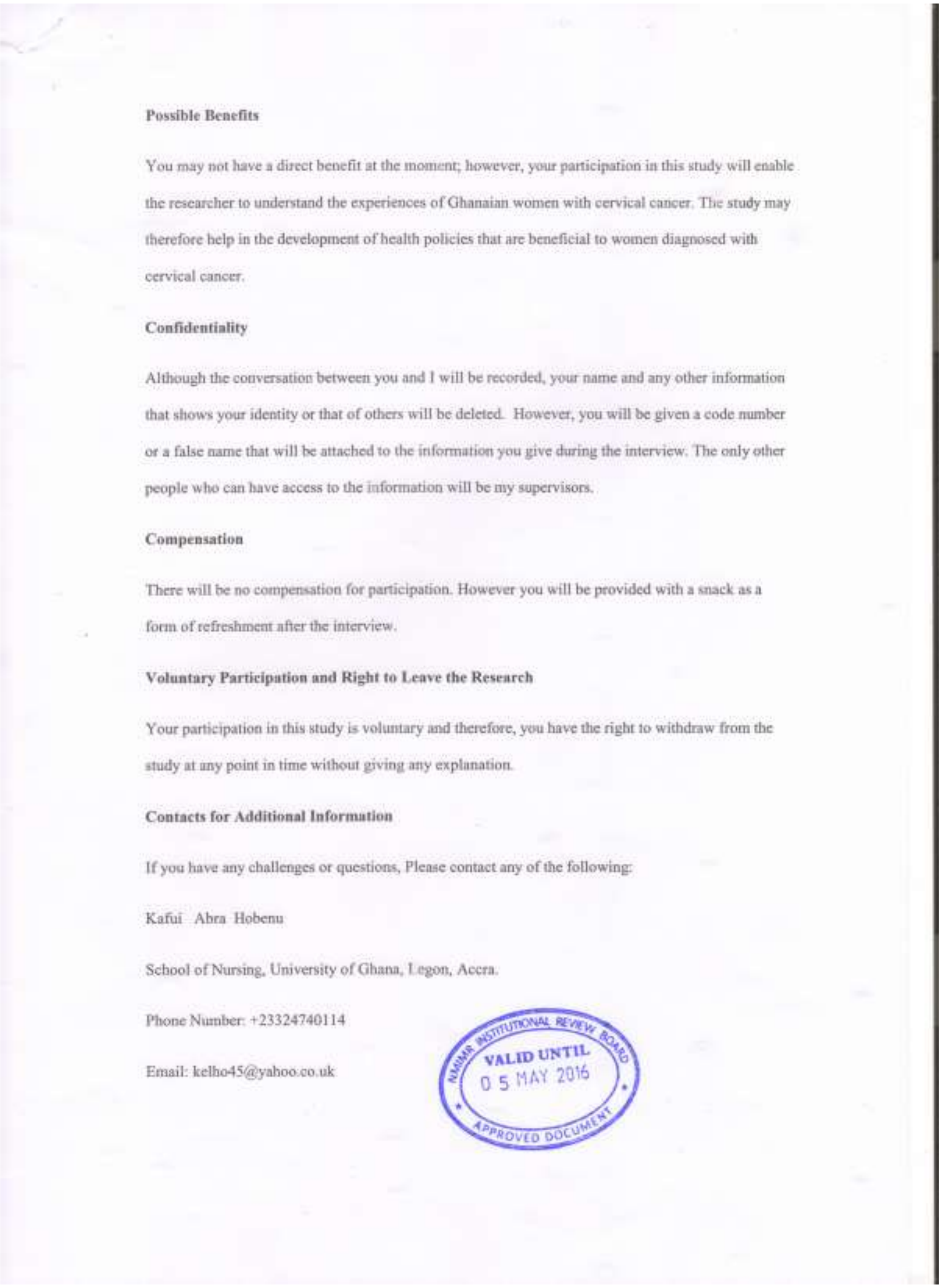
VALID UNTIL
05 MAY 2016
APPROVED DOCUMENT



Possible Benefits

You may not have a direct benefit at the moment; however, your participation in this study will enable the researcher to understand the experiences of Ghanaian women with cervical cancer. The study may therefore help in the development of health policies that are beneficial to women diagnosed with cervical cancer.

Confidentiality

Although the conversation between you and I will be recorded, your name and any other information that shows your identity or that of others will be deleted. However, you will be given a code number or a false name that will be attached to the information you give during the interview. The only other people who can have access to the information will be my supervisors.

Compensation

There will be no compensation for participation. However you will be provided with a snack as a form of refreshment after the interview.

Voluntary Participation and Right to Leave the Research

Your participation in this study is voluntary and therefore, you have the right to withdraw from the study at any point in time without giving any explanation.

Contacts for Additional Information

If you have any challenges or questions, Please contact any of the following:

Kafui Abra Hobenu

School of Nursing, University of Ghana, Legon, Accra.

Phone Number: +23324740114

Email: kelho45@yahoo.co.uk

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Dr. Lydia Aziato

School of Nursing, University of Ghana, Legon, Accra

Phone number: +233244719686

Email: aziatol@yahoo.com

Dr. Florence Naab

School of Nursing, University of Ghana, Legon, Accra

Phone number: +233 263741717

Email: florencenaab@yahoo.com

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.mimcom.org

VALID UNTIL
0 5 MAY 2016
APPROVED DOCUMENT

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title "Surviving Cervical Cancer: Experiences of women in the Accra Metropolis" has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

______________________ ____

Date Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

______________________ ____

Date Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

______________________ ____

Date Name Signature of Person Who Obtained Consent

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VALID UNTIL
0 5 MAY 2016
APPROVED DOCUMENT

Appendix G: Demographic Profile of Participants

Table 4. 2*:* Demographic Profile of Participants

Number /Pseudonyms	Age	Educational Level	Religion	Marital Status	Number of Children	Occupation	Number of years of Disease	Receiving treatment	Type(s) of treatment	Language(s) spoken	Age at 1st Sex	Number Sex partner(s)	History of smoking	Oral Contraceptive pills	Partner with multiple sexual partners	$1^{st}/2^{nd}$ marriage	Stage of disease
001 Mera	50	primary	Christian	Married	6	Farming	3 yrs	Yes	Radio + Chemo	Ewe	16	5	No	6 yrs	Yes	2nd Marriage	IIB
002 Merab	52	No education	Christian	Married	4	Farming	2 yrs	Yes	Radio + Chemo	Twi	17	5	No	5 yrs	Yes	2nd Marriage	IIB
003 Merac	33	Secondary	Christian	Relationship	3	Trading	1 yr.	Yes	Radio + Chemo	Ewe, English	15	7	No	3 yrs	Yes	None	IIIB
004 Merad	53	Primary	Christian	Divorced	6	Trading	2 yrs	Yes	Radio + Chemo	Ewe	14	6	No	5 1/2 yrs	Yes	2nd Marriage	IIB
005 Merae	67	Primary	Christian	Widow	6	Farming	2yrs	Yes	Radio	Ewe	15	5	No	6 yrs	Yes	2nd Marriage	IIIA
006 Meraf	41	Diploma	Christian	Married	4	Teaching	1 yr.	Yes	Radio + Chemo	Twi, English	16	5	No	5 yrs	Yes	2nd Marriage	IIB
007 Merag	63	Diploma	Christian	Married	3	Retired Banker	2 yrs	Yes	Radio + Surgery	Ewe, English, Twi	19	5	No	6 yrs	Yes	1st Marriage	IIA
008 Merah	43	Middle school	Christian	Married	3	Trading	1 1/2 yrs	Yes	Radio + Chemo +Surgery	Ewe	13	uncountable	No	4 yrs	Yes	2nd Marriage	IIB
009 Merai	46	Primary	Christian	Married	5	Trading	1 yr.	Yes	Radio + Chemo +Surgery	Twi	15	7	No	7yrs	Yes	2nd Marriage	IIIB
010 Meraj	50	Secondary	Christian	Divorced	4	Trading	1 yr.	Yes	Radio + Chemo	Fante, English	17	5	No	5 1/2 yrs	Yes	1st Marriage	IIB
011 Merak	34	Secondary	Christian	Single	None	Secretary	3 yrs	Yes	Radio + Chemo	English, Ewe	14	7	No	2 yrs	Yes	None	IV
012 Meral	38	Primary	Christian	Married	3	Trading	1 1/2 yrs	Yes	Radio	Ewe, Ga Adangbe	16	8	No	6 yrs	Yes	2nd Marriage	IIIB
013 Meram	38	Diploma	Christian	Married	2	Caterer	1 1/2 yrs	Yes	Radio + Chemo	Fante, English	15	4	No	3 yrs	Yes	1st Marriage	IIB
014 Meran	37	Secondary	Christian	Married	2	Beautician	1 yr.	Yes	Radio + Chemo	English, Ewe, Twi	15	6	No	6 yrs	No	2nd Marriage	IIB
015 Merao	35	Diploma	Muslim	Divorced	None	Radio Presenter	1 yr.	Yes	Surgery + Chemo + Radio	English, Hausa, Twi	18	3	No	2 yrs	Yes	1st Marriage	IIB