

Running Head: THE PSYCHOSOCIAL EXPERIENCES AND NEEDS OF WOMEN...

**The Psychosocial Experiences and the Needs of Women Patients Diagnosed With Cervical
Cancer: The Case of Black Lion Hospital Cervical Cancer Patients**

Konjit Kebede



A Thesis Submitted to the School of Social Work

**Presented in Partial Fulfillment of the Requirements for the
Degree of Masters of Art (Social Work)**

Addis Ababa University

Addis Ababa, Ethiopia

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This is to certify that the thesis prepared by Konjit Kebede entitled: The Psychosocial Experiences and Needs of Women Patients Diagnosed With Cervical Cancer: The Case of Black Lion Referral Hospital, in partial fulfillment of the degree of Master of Art (Social Work) complies with the regulations of the University and meets the expected standards with respect to originality and quality.

Signed by the Examining Board

Advisor

Signature

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Signature

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Chair of the Department or Graduate Program Coordinator

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Table of Contents

| Content | Page |
|---|-------------|
| Acknowledgements | |
| Table of Content | |
| Acronym | I |
| Abstract | II |
| CHAPTER ONE: INTRODUCTION | 1 |
| Background | 1 |
| Statement of the Problem | 3 |
| Objectives of the Study | 6 |
| General Objectives | 6 |
| Specific Objective | 6 |
| Research Questions | 6 |
| Significance of the Study | 7 |
| Definitions of Terms and Concepts | 7 |
| Organization of the Paper | 9 |
| CHAPTER TWO: LITERATURE REVIEW..... | 10 |
| Overview of Cervical Cancer in Ethiopia..... | 10 |
| Factors Affecting the Risk of Cervical Cancer | 13 |
| Human Papilloma Virus | 13 |
| Number of Sexual Partners and Age of First Sexual Intercourse | 14 |
| Sexually Transmitted Diseases and risk of Cervical Cancer | 15 |
| Hormonal Contraceptive use and Cervical Cancer | 15 |
| Age, Smoking and Risk of Cervical Cancer | 16 |
| Food habits and Diet..... | 17 |
| Family History as Risk Factors for Cervical Cancer | 17 |
| Socioeconomic Factors | 17 |
| Cervical cancer staging..... | 18 |
| Prevention of Cervical Cancer | 19 |
| Treatments of Cervical Cancer | 20 |
| Surgery | 20 |

| | |
|--|-----------|
| Radiation | 21 |
| Chemotherapy | 21 |
| Psychosocial Effects of Cervical Cancer | 22 |
| Conceptual Frameworks | 25 |
| CHAPTER THREE: RESEARCH METHODS | 27 |
| Research Method | 27 |
| Research Design | 27 |
| Study Site and Time Frame | 28 |
| Study Participants | 28 |
| Sampling Techniques and Participant Selection Procedure | 28 |
| Inclusion and Exclusion Criteria | 29 |
| Data Collection Techniques | 29 |
| In Depth Interview | 30 |
| Key Informant Interview | 31 |
| Document Review | 31 |
| Measures to Improve Trustworthiness | 31 |
| Ethical Considerations | 33 |
| Methods of Data Analysis and Presentation | 34 |
| Limitations of the Study | 34 |
| CHAPTER FOUR: FINDINGS OF THE STUDY | 35 |
| Socio Demographic Profiles of Participants | 35 |
| Information and Knowledge about Cervical Cancer | 37 |
| Experience towards Cervical Cancer Diagnosis Report..... | 38 |
| Emotional Responses and Reactions of Patients | 40 |
| Interpersonal Relationships and Concerns of Intimacy Following the Diagnosis | 42 |
| Role Performance after the Diagnosis..... | 44 |
| Sexual Life after the Diagnosis..... | 74 |
| Experiences of Patients towards Cervical Cancer Treatment..... | 48 |
| Life Management after the Diagnosis Result and In the Treatments Phases | 53 |
| Consultation about the Treatments Problems | 56 |
| Participation in Religious Activities and Other Voluntary Groups..... | 58 |

| | |
|---|-----|
| Needs of cervical cancer patients | 62 |
| Lack of Screening Services in Local Areas | 62 |
| Issues Related To the Treatment Services and Location | 62 |
| Financial Crisis Following to the Diagnosis | 65 |
| Issues of Satisfaction with the Existing Social Support Systems | 67 |
| Future Plans of Patients about Connecting With Family, Community and Treatment Follow Ups | 69 |
| Findings from Health Professionals | 70 |
| CHAPTER FIVE: DISCUSSION OF THE MAJOR FINDINGS | 77 |
| CHAPTER SIX: CONCLUSION AND IMPLICATIONS OF THE STUDY | 85 |
| Conclusion | 85 |
| Implication of the Study | 86 |
| Implication of Social Work Intervention | 86 |
| Implication for Social Work Education | 87 |
| Policy Implication | 87 |
| Implication for Health Practitioners and the Institution | 88 |
| References | 90 |
| Appendix A | 101 |
| Appendix B | 103 |
| Appendix C | 105 |
| Appendix D | 108 |
| Appendix E | 112 |
| Appendix F | 114 |

Acronyms

| | |
|-------|---|
| ACS | American Cancer Society |
| ART | Anitre Ritro Viral Treatment |
| CIN | Cervical Intraepithelial Neoplasia |
| DNA | <i>Deoxyribonucleic acid</i> |
| FIGO | International Federation of Gynecology and Obstetrics |
| HIV | Human Immune Deficiency Virus |
| HPV | Human Papilloma Virus |
| ICC | progression to invasive cervical Cancer |
| IES | Information Education and Communication |
| NASAW | National Association of Social Workers |
| NCI | National Cancer Institute |
| RT | Radiotherapy |
| STDs | Sexually Transmitted Diseases |
| TRASH | Tikur Anbessa Specialized Referral Hospital |
| VIA | Visual Inspection of Cervix with Acetic Acid |
| WHO | World Health Organization |

Abstract

Cancer is an emerging public health issue in Africa and in which Cervical cancer is count to be the second most widespread cancer among women. Despite the availability of large number of cancer patients in Ethiopia there is no national cancer control program and there is no cancer registration process. Moreover there is only one referral governmental health institution in the country for all cancer cases. The overall objective of this study was to explore and understand the psychosocial experiences and needs of women patients who are diagnosed with cervical cancer. This study was carried out in Black Lion Referral Hospital. A total of 15 participants (12 patients and 3 key informants) were purposively selected to take part in the study. The study employed a qualitative method with an exploratory case study design. Data was gathered through in-depth interviews made with the cases and key informants. In organizing the data, thematic content analysis method which involves transcription, translation, coding and categorization and theme development was employed. Findings of this study revealed that women who were diagnosed with cervical cancer have faced with tremendous physiological, psychological and social challenges as a result of their illness. The challenges they have faced following to their diagnosis and in the course of their treatments were not only exceptionally personal but affected various levels of their personal, family, professional and social lives. According to the finding of this study, lack of screening service in the origin, distant of the treatment location, inaccessibility of beds for treatment admission in the hospital, non-affordability of treatments, poor communication among the health professional and the patients, lack of information about the illness and its treatments, intimacy issues and separation from families and loved ones, remission of the illness after some stage of the treatments, financial crisis, depression and hopelessness were found to be patients psychosocial need during their diagnosis with cervical cancer and in the course of their treatments. However, participants also shared common coping mechanisms such as attending religious rituals, seeking social support systems during the diagnosis and in their treatments phases. The findings of this study suggests that the government should give a priority in the developing healthy milieu and increasing access to quality of health services to cancer patients, principally in regional level. Furthermore health social workers need to develop sensitive and responsive skills to assist patients to deal with their psychological, social, emotional, and spiritual needs during the diagnosis with cervical cancer and in the course of the treatments.

Key words: Cervical cancer, diagnosis, treatment, psychosocial, experience, need

Chapter One

Introduction

Background

Cancer is an emerging public health issue in Africa, with estimates of 715, 000 new cases and 542, 000 cancer deaths in the continent in 2008. A third of cancer deaths in Africa are potentially preventable, many are caused by chronic infection and tobacco use. An ageing and growing population, together with the adoption of lifestyle habits such as smoking, physical inactivity and injurious, high-calorie, western diets all contribute to the rise of cancer burden in Africa; projections suggest that cancer incidence and mortality will double to 128 million new cases and 970 000 deaths per year by 2030(WHO,2010).

Cervical cancer is the second most widespread cancer in women worldwide (471,000 annual cases, 233,000 deaths). It is estimated that around 83% per cent of all the new cases of cervical cancer and 85% of all the deaths occur in the developing countries. The highest incidence rates are observed in Sub-Saharan Africa, Latin America, the Caribbean, and South and Southeast Asia. In more developed countries, incidence rates are relatively low (Parkin, 2005; Sankaranarayanan and Ferla, 2006).

In Ethiopia, it is estimated that 20.9 million women were at risk of developing Cervical Cancer and the estimated annual number of Cervical Cancer cases and deaths are 7,600 and 6,000 respectively. It is projected that the number of new cervical cancer cases will almost double by 2025(WHO, 2011; Adiss Tesfa, 2010). These figures would substantially underestimate the actual number of cases given the perceived low level of awareness about the

disease, cost of transport and treatment, limited access to screening and treatment services, and the lack of a national cancer registry to enumerate cases.

The health policy of the Transitional Government of Ethiopia (1999) prioritizes the component of information, education and communication (IEC) to enhance the awareness of health issues. It pays special attention to the needs of women and the poor and the vulnerable. It also emphasizes that appropriate support shall be given to curative and rehabilitative services. However, the word 'cancer' is not used at any place in the policy document. The policy talks about communicable diseases but non-communicable and chronic diseases are not mentioned anywhere in the policy document. Cancer is a growing problem in Ethiopia but it is neglected (Tsigea Biru, 2012). Despite the availability of significant number of cancer patients in Ethiopia there is no national cancer control program and there is no cancer registration process. Moreover only a very limited research exists in the area. As a result, there is no accurate morbidity and mortality data available to convince policymakers on the issue. Furthermore, even for the existing cervical cancer patients, to the knowledge of the researcher, there is no program designed to address the psychosocial needs. Therefore, this study will try to explore the psychosocial experiences and the needs of women diagnosed with cervical cancer, thereby it would be possible to fill the knowledge gap and service providers and concerned bodies will have a better understanding of the lives and needs of cervical cancer patients.

Statement of the Problem

Cervical cancer is a gynecological malignant disorder and is a common cause of death in Women of the sub-Saharan Africa, striking nearly half a million of females die each year worldwide (WHO, 2010). According to Zeferino and Derchain(2006),

Cervical cancer is due to the persistence infection of human papillomavirus (HPV), a frightening Virus which targets the cervix and is present in most cancers of the cervix.

The highest rate of cervical cancer incidence is reported from Sub-Saharan Africa.

Among the Sub-Saharan African countries, East African countries bear the highest burden of the disease and the mortality caused by it (p.12).

The true incidence of cervical cancer in many African countries is unknown as there is a gross under-reporting. Only very few countries have functional cancer registries and record keeping is minimal or non-existent in many countries. Some of the figures quoted in the literature are hospital-based, which represents a small fraction of women dying from cervical cancer, as most women cannot access hospital care and die at home. A mortality rate of 35 women per 100,000 women is reported in Eastern Africa. On the other hand, the reported mortality rates in developed countries with successful screening programs seldom exceed 5 per 100,000 women (Chokunonga, 2002).

Several factors that place women at risk of developing cervical cancer have been identified. Some of these factors include multiple sexual partners, sexual intercourse at early age, smoking and a history of sexually transmitted diseases and Infection by virus known as human papilloma virus (HPV), which is sexually transmitted are said to be some of the contributors in the development of cervical cancer. Further more studies have found association between human

immune deficiency virus (HIV) infection and cervical cancer. HIV infected women are at greater risk of developing this cancer than those not infected (Berma and Grosen, 1995).

Qualitative multiethnic studies in USA, stated that Women with a cervical cancer diagnosis are disproportionately challenged by lack of resources including quality, affordable health care and psychosocial services (Kimlin , Ashing, and Marjorie, 2010). As stated in Kowalsk and Brown; (1994), Mullin, Misham, and Hubel, (2001), cervical cancer survivors also experience persistent medical, psychological, social, and relational concerns.

After being diagnosed with cancer, patients report in coping with work, caring for their family as well as severe pain that interferes with their general social life (Baileff, 2000). They indicate less satisfaction with their affected ability to perform household duties due to fatigue and they report the difficulty of sharing fear problems with others. When a forced deterioration occurs it calls for an individual to give up at least temporarily the autonomy and environmental mastery which characterizes the psychological mature adult.

Cervical cancer impacts on the family in many ways. Firstly it affects the intimacy between parent, because it result in reduced libido, moreover, depending a stage and level at which the illness is diagnosed; the motor is at risk of dying and leaving young children behind. (Eisemach and Lalos ,1999).

According to Truk (1999), failure to diagnose cervical cancer at an early stage results in the illness being chronic. It becomes reversible and it also assaults on multiple areas of functioning beyond the physical body. A very few existing studies in Ethiopia with regard to this issue stated that lack of awareness and health seeking behavior for cancer are common due to misconceptions about the cause of the disease (Zewdie, Alemseged andTefera, 2012). Moreover, a quantitative research done by Mulugeta (2011), to assess the adult cancer patients' opinion

towards cancer chemotherapy related information needs in Tikur Anbessa Specialized Referral Hospital(TASRH) in Addis Ababa revealed that majority of the study participants were with the poor provision of the most essential chemotherapy related information. Surprisingly, great majority of them did not know the name of chemotherapy they have taken or currently taking.

Alemayehu (2011), a public health study which aimed at estimating both the direct and indirect costs associated with cervical cancer in Ethiopia has found that cervical cancer creates an immense economic burden on patients and their families. It also regarded cervical cancer as costly disease, in which the poor, vulnerable, and uneducated were the segment of population who suffered at most.

From the above statement it is evident that, the high prevalence of the disease in Ethiopia calls for special attentions to patients, as cervical cancer is a health problem; demanding attention and public health priority from health program mangers, planners, policy designer and social workers. But limited information exists both on the issue and the patients understanding of the disease in general and cervical cancer in particular, due to this lack of knowledge professionals are not at the right position to assist the patients effectively and deliver services to them efficiently. Therefore, the aim of this research is to explore the psychosocial experiences and needs of female patients who are diagnosed with the cervical cancer and have already started treatment.

Objectives of the Study

General objective: The overall objective of the research is to explore the psychosocial experiences and the needs of women patients diagnosed with cervical cancer.

Specific objectives: Specific objectives of the study include achieving the following specific issues.

1. To assess women patients responses and reactions of cervical cancer diagnosis and treatment.
2. To identify how cervical cancer affects the emotional, psychological social well beings and family relations of the female patients.
3. To assess the needs and coping mechanisms of women patients diagnosed with the cervical cancer.

Research Questions

This study tries to explore and answer the following questions.

1. What are the psychosocial experiences of patients diagnosed with cervical cancer?
2. How do patients interpret and respond to cervical cancer diagnosis and treatment?
3. How cervical cancer affects the emotional, psychological social well beings and family relations of the female patients?
4. How a woman does manage her life, having acquired chronic health problems of cervical cancer?

Significance of the Study

This study has a tremendous significance in the areas of Oncology service delivery and in policy development, as well as in health care Social work profession and knowledge building work regarding the health, social and psychological difficulties of cervical cancer patients. Health Social workers have responsibilities with a direct impact on the health and well-being of people. According to the National Association of Social Workers (NASAW) (2003), social workers have an important role in recognizing treatment needs, provide treatment, rehabilitation, supportive care, enhancement of social functioning and linking clients to the appropriate support and services in health care settings. Hence, a better and concrete understanding of how people with chronic form of illness seek and follow medical services will equip social workers with more sensitive and responsive skill in providing and facilitating the treatment process based on the patients needs and their specific situation.

In general, considering the shortage of researches that targeting cancer related (oncology) issues as a whole and the experience of women with cervical cancer illness in particular this study has a paramount importance for the country in providing basic consideration of patients diagnosed with cervical cancer. This study contributes to the knowledge gap observed as a result of the scarce information on psychosocial experiences and the needs of women with cervical cancer in Ethiopia. Besides to the academic circles, service providers including social workers may appropriate their services to be able to address the issue. Furthermore, researchers can use the findings as inputs for further studies.

Definitions of Terms and Concepts

Psychosocial: Dorland's illustrated medical dictionary (1994) states that psychosocial pertain to both psychic and social aspects. The term psychic is further conceptualized as

pertaining to the psyche or mind i.e. the human faculties and capabilities of thought, judgment, and emotions, unconscious and conscious processes (Dorland's illustrated medical dictionary, 1994). Blackstone's Gould medical dictionary (1999) and the Oxford concise dictionary (1997) define psychosocial as all those psychological and social factors as well as all human interactive behavior. The parameters of psychosocial for this study are all those psychological, social, emotional, cognitive factors and behaviors of patients diagnosed with cervical cancer.

Experience: This term is self-exploratory. The Oxford concise dictionary (1997) defines experiences as actual observation of practical links with the facts and events and which leaves a lasting impression. This therefore suggests views and perception of patients.

Needs: Merriam Webster's dictionary (2006) and the Oxford concise dictionary (1997) define a need as a lack of something requisite, desirable and as a condition requiring provision or relief. Therefore, the need for this study is social as well as psychological requirement for the well-being of cervical cancer patients.

Women patients: For this study, women patients are cervical cancer patients who are under medical care and treatments starting from age eighteen.

Diagnosis: This refers to a diagnosis being placed on the individual. Dorland's illustrated medical dictionary (1994) establishes diagnosis or to be diagnosed as the determination of the nature of the disease or the art of distinguishing between the diseases. The Oxford concise dictionary (1997) states it as identifying disease as according to the diseases. The diagnosis or to be diagnosed can therefore be viewed as nothing more than a classification or a label as a result of symptoms e.g. cervical cancer.

Cervical Cancer: Cervical cancer is generally defined as a disease characterized by the abnormal growth of cells in the cervix, the region of the uterus that joins the vagina. Dorland's

illustrated medical dictionary (1994) describes cervical cancer as Cervical cancer as an infection in which the cells of the cervix become abnormal and start to grow uncontrollably, forming tumors and common cause of cancer deaths in women. In light of this study, cervical cancer will be considered as those abnormal growths of cells of cervix, which necessitate treatment.

Organization of the Paper

This study is organized into five chapters. The first chapter provides the background information about the study. The second chapter deals with the review of literature related to cervical cancer. The third chapter contains research design and methodology. The fourth chapter deals with the findings, in fifth chapter discussion of the major findings will be presented. The fifth chapter includes the conclusion and implications of the study.

Chapter Two

Literature Review

Overview of Cervical Cancer in Ethiopia

Cervical cancer is responsible for about 27,500 deaths every year. That number is drastically lower than what it was prior to the 1960 and continues to decline at about four percent per year. Yet according to cancer research in UK, cervical cancer is the most common cancer in women, accounting for approximately 530,000 new diagnoses annually. About 88 percent of cervical cancer deaths occur in low income or middle income countries (WHO, 2010; Parkin, Bray, and Ferlay, 2005; Kitchener, Castle, Cox, 2006; Sankaranarayanan, and Ferlay, 2006).

Cervical cancer is the first most common cancer in women in sub Saharan Africa followed by breast cancer. Cervical cancer is one of the leading causes of cancer related deaths among women in Ethiopia (Ntekim, 2012). Even though data on cervical cancer morbidity and mortality in Ethiopia is scarce and generally based on hospital, according to Pathfinder (2010) of the estimated 22 million Ethiopian women over the age of 15, approximately 7,600 diagnosed with cervical cancer and roughly 6,000 women die of the diseases each year. These figures are probably significantly lower than the actual number of cases, give the low level of awareness, cost and limited access to screening services and lack of a national cancer registry. In Ethiopia, the incidence of cervical cancer is relatively high because of the high prevalence of HIV, which affects more than 500,000 women in Ethiopia. The cause of cervical cancer is the human papilloma virus, a sexually transmitted infection. Women who are HIV positive can't effectively fight off HPV and are more likely to become infected and progress to full-blown cervical cancer (Ruthann; 2009, Fekadu , Mulunesh and Zelalem ,2012).

As a major public health problem, the disease disproportionately affects the countries most vulnerable: poor, rural, and HIV positive women, who more likely to develop cervical cancer if not treated in its early infection. Given the effectiveness of Antiretroviral treatment (ART) under the growing number of HIV positive women who are living longer, especial attention must be focused on screening and treatment for this population. Though Cervical cancer is preventable and, in most cases curable, if identified in its early stage, but Ethiopian women, by the time they seek screening services the cancer is often at an advanced stage (Adnew, Davila, Blumenthal, Shiferaw, Ansel and Sisay, 2009).

According to The Ethiopian Herald (2013, September 22), “there is no cervical cancer-screening program in place in the country, so most women are diagnosed at an advanced stage, when there is no hope of recovery.” Women in the early stages of the disease have no symptoms, so wouldn’t suspect any illness, as cervical cancers may develop over a period of 10 to 20 years, early detection and treatment is critical. The cancer is curable if caught at an early stage, and preventable if the pre-cancerous state is discovered. According to an interview made by *Tadias Adis* magazine (2012) with the Oncology Unit at Black Lion Hospital has documented that “Every year the unit takes at least 7,000 newly diagnosed patients but the waiting time to start treatment is usually more than 6 months,” In the meantime a large number of patients die without any help or any source of pain relief.

The health policy of the Transitional Government of Ethiopia (1993) prioritizes the component of information, education and communication (IEC) to enhance the awareness of health issues. It pays special attention to the needs of women and the poor and the vulnerable. It also emphasizes that appropriate support shall be given to curative and rehabilitative services. However, the word 'cancer' is not used at any place in the policy document. The policy talks

about communicable diseases but non-communicable and chronic diseases are not mentioned anywhere in the policy document. According to Addis Mulugeta (2009), Ethiopia does not have a record of how many people are affected by cervical cancer, but the number is growing.

Treating the disease with very limited resources in a country like Ethiopia is very difficult and expensive and the outcome of the treatment is also very discouraging, as most of the patients come for treatment too late.

Scientific and public health advances have made cervical cancer one of the most preventable and treatable malignancies. Cytology-based screening (Pap smear test) has significantly reduced cervical cancer incidence and mortality in developed countries (American cancer society, 2002). Yet it has had limited success in Ethiopia and other resource-poor countries, as it requires repeated testing, laboratory analysis, and proper diagnostic, treatment, and follow-up protocols. Ethiopia has invested little in the infrastructure, training, and laboratory capacity required for successful Pap smear screening. As a major public health problem, the disease disproportionately affects the country's most vulnerable: poor, rural, and HIV-positive women (Addis Tesfa; 2010, Addis Mulugeta ; 2009). Alemayehu (2011), public health study which aimed at estimating both the direct and indirect costs associated with cervical cancer in Ethiopia has found that cervical cancer creates an immense economic burden on patients and their families. It also regarded cervical cancer as costly disease, in which the poor, vulnerable, and uneducated were the segment of population who suffered at most.

Factors Affecting the Risk of Cervical Cancer

Human Papillomavirus: Human Papillomavirus (HPV) is the cause of almost all types of cervical cancer. It is now an established fact. Human Papillomavirus is the etiological agent which has a causal relationship with cervical cancer(Clifford , Gallus , Herrero , Munoz , Snijders ,and Vaccarella , 2005).The prevalence level of HPV types in various parts of the world varies and thus the risk of cervical cancer caused by the infection also varies. A study conducted by Clifford and coworkers reveals that the infection of HPV in the women of Sub-Saharan Africa is five times more than in the women of Europe. There are around 100 different types of HPV but all are not reported to be causal agents of cervical cancer and only 40 of them infect the human genital tract. In a meta-analysis it was found that around two-thirds of all the cervical cancer is caused by HPV 16 and HPV 18. HPV 16 was responsible for 51% of the cervical cancer and HPV 18 was responsible for 16% (Clifford, Smith, Plummer, Muñoz , and Franceschi, 2003).

There are epidemiological evidences that in over 90% of the cervical cancer cases, HPV viral DNA was found in the cellular genome of the cervical carcinoma. Millikan and coworkers found that a greater number of cases with cervical intraepithelial neoplasia (CIN) can be a result of the infection caused by HPV. They concluded that the natural history of HPV has an etiological association with cervical cancer (Millikan, 1994). Anorlu (2003) reported that women in Sub-Saharan Africa have the highest prevalence of all HPV types. The women in this region are also susceptible to multiple infections with high-risk types. They also reported that this situation may be because of reasons such as HIV infection, low cellular immunity, parasitic infection, micronutrient deficiency and chronic cervical inflammation.

The prevalence of HPV 16 and/or HPV 18 among the women with normal cytology is not available for Ethiopia but prevalence of HPV 16 and/or HPV 18 among the women with cervical cancer was reported to be 90.2% (as reported in January 2010). HPV burden in healthy Ethiopian men has been reported to be around 73%. HPV can easily be transmitted from men to women and from women to men (Todd, Cremin , McGrath Bwanika , Wringe, and Marston, 2009).

Number of Sexual Partners and Age of First Sexual Intercourse: The number of sexual partners has a direct bearing on the risk of cervical cancer. The risk increases with the increase in the number of sexual partners. The women with one sex partner are at low risk of cervical cancer compared to women who have five or more sex partners. Green and coworkers reported that the trend in the risk with the number of sex partners is highly significant. Evidences from the case control studies show that women with cervical cancer reported more number of sexual partners (Green, Berrington, Gonzalez, Sweetland, Beral, Chilvers, and Crossley, 2000).

The age of first sexual intercourse is directly related to the risk of cervical cancer. The women who started their sexual life early are more at risk than women who started their sexual life late. Several studies reveal that those women who started their sexual life before the age of 16 years were at double the risk than those women who started their sexual life after 20 years. This is because the period of exposure to HPV is increased for these women (Green, Berrington, Gonzalez, Sweetland, Beral, Chilvers, and Crossley, 2003). According to Todd, Cremin , McGrath Bwanika, Wringe , and Marston (2009), The reported median age of first sexual intercourse in Ethiopia is 16.1 years for young women (15 to 24 years) and 21.2 years for men. It is also reported that 16% of the young women (15-24 years) have their first intercourse before the age of 15 years.

Sexually Transmitted Diseases and Risk of Cervical Cancer: The history of the presence of sexually transmitted diseases (STDs) is a risk factor for cervical cancer. Multiple STDs are cofactors for cervical cancer. Schmauz and coworkers reported that a number of such infections are associated with the increased risk of cervical cancer (Schmauz , Okong , Villiers , Dennin , Brade, and Lwanga, 1989). Human immune deficiency virus (HIV) which is responsible for immune suppression significantly increases the risk of cervical cancer in comparison to the women who are not infected with HIV (Weissen, Funke, Hellmich, Mallmann, Fuchs, and Pfister, 2003). Smith and coworkers reported that *Chlamydia trachomatis* increased the risk of cervical cancer among HPV positive women. They also concluded that *Chlamydia trachomatis* was found to be a possible cofactor for HPV in the etiology of cervical cancer (Smith, Muñoz, and Herrero, 2002).

Duncan and coworkers, in a study of Chlamydia infection in 1,846 women attending obstetric, gynecological and mother and child health clinics in Addis Ababa reported that 50% of the women had clinical evidence of past or present infection of Chlamydia. They also concluded that low income, bar-girl occupation, woman with five or more sex partners and Amhara ethnicity were at risk. (Duncan, Jamil, Tibaux, Pelzer, Mehari, and Darougar, 1996). Since HIV attacks the immune system, co-infection with HPV and HIV undermines the ability of the immune system to fight the HPV. In this way, HIV may cause HPV persistence or speed up progression to invasive cervical cancer (ICC). This synergy is of concern especially in Ethiopia where HIV prevalence is high and anti-retroviral therapy (ART) is not widely accessible.

Hormonal Contraceptive Use and Cervical Cancer: According to Beral, Berrington , Colin, and Franceschi (2007), there is strong evidence that current and recent use of the

combined oral contraceptive pills is associated with increased risk of cervical cancer among women. The relative risk of cervical cancer increases with the duration of the use of combined oral contraceptives and the relative risk come down once the use of these contraceptives is stopped. The risk goes down with time and after ten years of not using these contraceptives the risk comes down similar to the women who never used these contraceptives. It is also reported that the use of progestagen only inject-able contraceptives also makes a small increase in the risk of persistent cervical cancer. A comparison of women between developed and less developed countries who used combined oral contraception for ten years from the age of 20 years shows that the cumulative incidence per 1000 women at the age of 50 years was more in less developed countries than in developed countries. The incidence in less developed countries was almost two fold more than that of developed countries. In Ethiopia the use of oral contraception is 3.1% (Barcelon, 2010).

Age, Smoking and Risk of Cervical Cancer: Older women are at a higher risk of cervical cancer. Women aged 60 years and above form a significantly higher number of cervical cancer patients (Fox, Shah, Swisher, Garcia, Mandel, and Gray, 2008). Haverkos and coworkers reported that smoking is one of the risk factors of cancer of the cervix (Haverkos, Soon, Steckley, and Pickworth, 2003). According to Giuliano, Sedjo, Roe, Harri, Baldwi, and Papenfuss,(2000) Other prospective study, reported that among the smokers the duration of the HPV infection increases and this result in early cause of cancer. They also reported that among the smokers, the probability of self-clearing reduces cancer infections. A study conducted among smoking women who have minor-grade lesions reveals that smoking cessation has beneficial effects on early cervical abnormalities. The study suggested that there was a significant correlation between the extent to which smoking was reduced and the mass of the injury. This

suggests the possible role of smoking and HPV infection (Szarewski , Jarvis , Sasieni , Anderson , Edwards, and Steele, 1996). In Ethiopia the prevalence of smoking of any tobacco by men is 5.8% and by females is 0.6 % (Barcelon, 2010).

Food Habits and Diet: So far research has not proved that food and dietary intake has any kind of causal relationship with cervical cancer among women. However, epidemiological investigations suggest that there is some kind of protection among the women who consume more fruits and vegetables. Case control and prospective studies reveal that those women whose diet was rich in vitamin C, E and carotene had less chances of getting cancer (Glade, 1999).

Family History as Risk Factors for Cervical Cancer: Another risk factor is genetic susceptibility. Studies suggest that there is a genetic susceptibility to HPV. It is found that a few individuals are able to clear the early infection but a most of women are not able to do so. The relative risk of cervical cancer is more in the women where there is a family history of cancer of the cervix. The genetic factors play an important role in developing the response of the body to the infection of HPV. It can be concluded that genetic factors play a significantly important role in determining the risk of developing cervical cancer (Magnusson, 2000).

Socioeconomic Factors: According to Zeferino and Derchain (2006), cervical cancer is a main problem of the developing countries and the burden of the disease are borne by the poor women in these countries. Inadequate resources in the developing world including Ethiopia result in the inequitable burden of cervical cancer. Cervical cancer is identical to poverty and disease of poor women (Alemayehu, 2011). Poverty alone is a very important barrier for education, prevention, treatment and care of cervical cancer patients. In a study in Mali it was found that within a population widely infected with HPV, poor social conditions, sanitation and

high parity were the main factors for cervical cancer. A study conducted in Botswana revealed that the knowledge of screening tests and cervical cancer was inadequate among the women of low-income groups (Bayo, Bosch, Sanjosé, Muñoz, Combata, and Coursaget, 2002). According to McFarland (2003), women from low socio-economic background have been shown to have an increased risk of developing cervical cancer. Poor access to screening is responsible for this disparity. Sub standard nutritional status is another possible risk for women from impoverished backgrounds to develop cervical cancer more than their affluent counter parts.

In general with the above literature verifications though the unavailability of screening service in local area, the low awareness about the disease, early marriage, sexually transmitted diseases such as HIV as well as the poor socio- economic conditions of women is the challenge in Ethiopian context, the best ways to minimize the risk of cervical cancer are to have protected sex and avoid multiple sexual partners, eat a healthy diet, exercise regularly and see a doctor for checkup.

Cervical Cancer Staging

According to WHO (2006), staging is a method that has been developed to describe the extent of cancer growth. The stage of cervical cancer describes the tumors: size, depth of penetration within the cervix, spread within and beyond the cervix. Staging allows the physician to customize cancer treatment and to predict how a patient will fare over time. In general, the lower the stage, the better the person's prognosis (expected outcome). Cervical cancer staging is usually described in terms of a staging scheme developed by the International Federation of Gynecology and Obstetrics (FIGO). The FIGO classifications are grouped within basic stages

labeled stage one through stage four (American Cancer Society, 2012). The stage is based on where cancer is found. These are the stages of invasive cervical cancer.

Stage I: Cancer cells are found only in the cervix.

Stage II: The tumor has grown through the cervix and invaded the upper part of the vagina. It may have invaded other nearby tissues but not the pelvic wall (the lining of the part of the body between the hips) or the lower part of the vagina.

Stage III: The tumor has invaded the pelvic wall or the lower part of the vagina. If the tumor is large enough to block one or both of the tubes through which urine passes from the kidneys, lab tests may show that the kidneys aren't working well.

Stage IV: The tumor has invaded the bladder or rectum. Or, the cancer has spread to other parts of the body, such as the lungs.

Prevention of Cervical Cancer

Cervical cancer is fully preventable and curable, at low cost and at low risk if detected through screening and treated at an early stage (Adnew, Salvador, Blumenthal, Shiferaw, Ansel, and Sisay, 2009; Lewis, 2004). The screening for cervical cancer is based on two assumptions. The first is that prevention is better than cure and the second is that early detection may allow early treatment as the primary pathologic process is still reversible. Screening tests are relatively simple procedures that separate healthy persons from those with a high probability of having the disease (Zanotti and Kennedy, 1999).

According to Denny and Quinn (2006) “there are different methods of screening for cervical cancer. Some popular screening methods are Papanicolaou (Pap) smear, visual

inspection of cervix with acetic acid (VIA), HPV DNA test and colposcopy. Each test has its advantages and disadvantages and applicability in a specific situation’’ (p.23).

Cervical cancer screening requires infrastructure, human resources, quality assurance, monitoring and evaluation of the screening programs and financial means in general (Kitchener and, Symonds, 1999). Well-organized programs to detect and treat the early stages of cancer prevent up to 80% of cervical cancers deaths in developed countries. However, low coverage of cervical cancer screening is a serious problem and a major barrier in reducing the mortality and morbidity in the developing countries. Specifically in Sub-Saharan Africa very few women are ever screened for cervical cancer (WHO, 2007). According to Barcelon (2010), in Ethiopia coverage of screening for cervical cancer is also very poor. The national average for the country is 0.6% in the age group of 18 to 69 (rural and urban). The coverage in the rural area is 0.4% for the same age group.

Treatments of Cervical Cancer

Treatment options for cervical cancer may include surgery, radiotherapy (RT) and chemotherapy (American cancer society, 2012). Each one of them will be discussed in detail below.

Surgery: A simple surgical removal of uterus is used to treat some stages 0 and IA cervical cancers. Usually only the uterus is removed, although occasionally the fallopian tubes and ovaries are removed as well. The tissues adjoining the uterus, including the vagina, remain intact. The uterus may be removed either through the abdomen or the vagina. Women who have had the surgery cannot become pregnant, but complications from a hysterectomy are rare. If cervical cancer recurs following treatment, a pelvic exenteration (extensive surgery) may be performed.

This includes a radical surgery, with the additional removal of the bladder, rectum, part of the colon, and/or the entire vagina. Such operations require the creation of new openings for the urine and feces. A new vagina may be created surgically. Often the clitoris and other outer genitals are left intact. Recovery from a pelvic exenterating may take six months to two years. This treatment is successful with 40-50% of recurrent cervical cancers that are confined to the pelvis. If the recurrent cancer has spread to other organs, radiation or chemotherapy may be used to alleviate some of the symptoms.

Radiation: Radiation therapy, which involves the use of high-dosage of x- rays or other high-energy waves to kill cancer cells, often is used for treating some stages cervical cancers, or in combination with surgery. With external-beam radiation therapy, the rays are focused on the pelvic area from a source outside the body. With implant or internal radiation therapy, a capsule of radioactive material is placed internally, near the tumor. Alternatively, thin needles may be used to insert the radioactive material directly into the tumor. As stated in Kornblith (1998) radiation therapy, may have side effects such as skin reaction in the area of treatment, fatigue, premature menopause in young women, upset stomach and loose bowels, problems with urination, may lead to pain during sexual intercourse.

Chemotherapy: Chemotherapy, the use of one or more drugs to kill cancer cells, is used to treat disease that has spread beyond the cervix. Most often it is used following surgery or radiation treatment. The common drugs used for cervical cancer are cisplatin, ifosfamide, and fluorouracil. These may be injected or taken by mouth. Side effects of chemotherapy may include nausea and vomiting, fatigue, changes in appetite, hair loss, mouth or vaginal sores, infections, menstrual cycle changes, early menopause, infertility, bleeding or anemia (low red

blood cell count). According to American national cancer institute's With the exception of menopause and infertility, most of the side effects of chemotherapy are temporary and the side effects depend on a number of factors, including the type of drug, the dosage, and the length of the treatment.

Psychosocial Effects of Cervical Cancer

Chronic illness can bring about guilt, feelings of loss of control, anger, sadness, confusion, and fear (Charmaz, 2000; Stanton, 2001). Even though significant improvements to survival rates have occurred due to advances in detection and treatments, cancer remains a potentially life-threatening disease; as such, it represents a potentially catastrophic stressor to those diagnosed (Kilbourn and Durning, 2003). According to Andrykowski, Carpenter, and Munn, (2003), immediate reactions to the diagnosis of cancer may include disbelief, denial, anger, depression, anxiety, and confusion. As stated in Kornblith (1998), mood disturbance, fear of recurrence, concerns about body image, and communication problems with family members are common in cancer patients after diagnosis.

After being diagnosed with cancer, patients report in coping with work, caring for their family as well as severe pain that interferes with their general social life (Baileff, 2000). They indicate less satisfaction with their affected ability to perform household duties due to fatigue and they report the difficulty of sharing fear problems with others. When forced deterioration occurs women surrender at least temporarily from the autonomy and environmental mastery that characterizes the psychological mature adult.

At different stages of the cancer experience, different stressors affect the emotional and psychological well-being of the patient. Once the course of treatment has been established, the

patient may have to cope with discomfort from surgery and side effects from chemotherapy or Radiation. There can be pain, nausea, and fatigue. In addition, patients may need to cope with temporary or permanent cosmetic changes such as hair loss or the loss of a limb or reproductive organ resulting from surgery. The patient may fear abandonment, may be unable to perform sexually, or may be afraid of risking further pain with certain physical exertion (Andrykowski, 2003). In all instances, the primary coping task for the patient is to be able to minimize the experience and impact of these side effects in order to continue with as many routine daily activities and social roles as possible. In doing so, the patient is more likely to maintain the morale and motivation necessary to complete his or her treatment.

According to Vess (1998), during the treatment phase, “a major concern for some patients is their physical decline and the threat to psychological and financial well-being. Because many patients are unable to work during their treatment, they miss the sense of self-esteem and pride they used to get from their work. This casts many patients in only the sick role. The very real concern, faced by many, of financial insecurity and significant loss of family income forces some debilitated cancer patients back to work before they are able. In addition, physical decline, which prevents patients from fulfilling their former duties in the home, provokes frustration and anxiety” (Vess, 1998 p.9).

Patients may also experience more generalized worry; fear for the future; inability to make plans; uncertainty and a heightened sense of vulnerability; and other worries, such as about changes in sexual function and reproductive ability, and changes in one’s role within the family and other relationships (IOM and NRC, 2006). Moreover, cancer patients can face spiritual and existential issues involving their faith, their perceived relationship with God, and the possibility and meaning of death. Some cancer survivors report feelings of anger, isolation, and diminished

self-esteem in response to such stress (NCI, 2004). According to Kornblith (1998), The prevalence of psychological distress experienced by patient varies by type of cancer, time since diagnosis, degree of physical and role impairment, amount of pain, prognosis, and other variables.

According to Kimlin, Ashing, and Marjorie (2010), women who are diagnosed with cervical cancer are disproportionately challenged by lack of resources including quality, affordable health care and psychosocial services. As stated in (Kowalsk and Brown; 1994, Mc Mullin, Misham, and Hubel, 2001) Cervical cancer survivors also experience persistent medical, psychological, social, and relational concerns.

Cervical cancer impacts on the family in many ways. Firstly it affects the intimacy between parent, because it result in reduced libido, moreover, depending a stage and level at which the illness is diagnosed; the motor is at risk of dying and leaving young children behind (Eisemach and Lalos ,1999).

Emotional correlates to adjustment include the buffering effect of higher levels of social support, optimism, and degrees of communication with health care providers. The strongest predictor of positive adjustment is social support. Social support has been documented as having a major role in reducing or buffering negative psychological responses such as hopelessness, despair, and depression in cancer patients. Having someone to whom patients can confide their fears and concerns, a loving and supportive spouse or friend, appears to enhance their emotional state while facilitating the ability to cope more effectively with their illness (Blanchard, Albrecht, Ruckdeschel, Grant, and Hemmick, 1995). Hopelessness has a particularly corrosive impact on the cervical cancer patient's emotional state. Patients who perceive cancer as a death threat and view their life as meaningless have more symptoms of depression, with hopelessness

as an outcome of those feelings. Patients who have less social support have more symptoms of hopelessness (Gil and Gilbar, 2001).

Conceptual Framework

Conceptualization fostered clarity regarding the purpose of the research. The bio-psychosocial model (theory) as according to Engel, (1977) will now be discussed in relation to the purpose of this study.

The bio-psychosocial and spiritual model posits the importance of understanding the biological, psychological (which entails thoughts, emotions, and behaviors), and social (socio-economical, socio-environmental, and cultural) factors, that plays a significant role in human functioning in the context of disease or illness. This is in contrast to the traditional, reductionist biomedical model of medicine that suggests every disease process can be explained in terms of an underlying deviation from normal function such as a pathogen or injury (Engel, 1977). According to Santrock (2007), health is best understood in terms of a combination of biological, psychological, and social factors rather than purely in biological terms. Furthermore, critics of this model have further proposed spiritual constructs which also affect an individual's disease or illness.

Some thinkers see the bio-psychosocial model in terms of causation. On this understanding the biological component of the bio-psychosocial model seeks to understand how the cause of the illness stems from the functioning of the individual's body. The psychological component of the bio-psychosocial model looks for potential psychological causes for a health problem such as lack of self-control, emotional turmoil, and negative thinking. The social part of the bio-psychosocial model investigates how different social factors such as socioeconomic

status, culture, poverty, technology, and religion can influence health (Santrock, 2007; DiMatteo, Haskard, and Williams, 2007).

The bio-psychosocial model presumes that it is important to handle the three together as a growing body of empirical literature suggests that patient perceptions of health and threat of disease, as well as barriers in a patient's social or cultural environment, appear to influence the likelihood that a patient will engage in health-promoting or treatment behaviors, such as medication taking, proper diet and engaging in physical activity (DiMatteo, Haskard and Williams, 2007). The relationship between how the mind, environment and social factors influence the physical health of the body has been proven in more recent times, especially in the treatment of chronic conditions such as cancer (Becker, and Rosenstock, 1997).

Cassilth and Lief (1999) view cancer as bio-psychosocial disease as it not only affects the biological (physical) aspects but also the social and psychological aspects. A cancer diagnosis not only elicits anxiety but also disrupts the lives of the patients such as routines, tasks, responsibility, etc. The bio-psychosocial model implies that treatment of disease processes in cancer requires that the health care team to address the biological, psychological and social influences of the disease upon a patient's functioning (Halligan and Aylward, 2006).

Therefore to explore and understand the psychosocial experiences and the needs of cervical cancer patients holistically, the bio-psychosocial and spiritual model is used as a conceptual framework for this study.

Chapter Three

Research Method

Research Design

Qualitative research method with special emphasis given to intrinsic case study research design was employed for this study. The rationale behind using qualitative research method with a case study design was that qualitative research is well suited for understanding phenomena within their context, discovering links among concepts and behaviors (Patton, 2002; Campbell and Gregor 2004; Quinn 2005). In addition qualitative research method is particularly relevant to public health because of the need to describe and understand people (Pope, Ziebland, and Mays, 2000). A qualitative research method is appropriate for this study because the aim is to understand and describe human experiences, namely what it is like to live with a diagnosis cervical cancer. In this study a qualitative research will provide an insight into how women patients make sense of their psychosocial experiences of cervical cancer. Human emotions or experiences are not easy to quantify or assign numerically therefore a qualitative approach is appropriate (Burns, and Grove, 1999). According to Cresweell(2009) qualitative method is a means of exploring and understanding the meaning individuals or groups ascribe to social and psychological problem. Moreover, Epstein (1998), states that qualitative research utilize inductive reasoning (drive concepts from social entities), and seek the essential character of social and psychological phenomena.

Case study design according to Yin (2003) contributes to acquiring knowledge of the individual, organization, social and political phenomena. According to Kreuger and Neuman (2006), a case can be a group, community, school, family, organization, individuals, geographic

unit or an event. Evidences from more than one case are often considered to be stronger than evidences from a single case. Among the different types of case studies, in this research, Multiple case study are studied where a cases refers to patients who are diagnosed with cervical cancer.

Study Site and Time Frame

The study was conducted in Tikur Anbessa Referral Hospital specifically on Gynecology and Radiotherapy Departments. Tikur Anbessa Referral Hospital is the only central referral hospital in the country and it is expected to provide specialized services for more than 80 million people. According to Alemayehu (2011), the radiotherapy center which is located in Tikur Anbessa Hospital is the only institution which provides radiotherapy and chemotherapy for cancer patients in the country. The schedule for the study was from March to May, 2014.

Study Participants

Data were collected from women patients who are diagnosed with cervical cancer and started treatment in Tikur Anbesa Referral Hospital. Cervical cancer patients who are being treated in the Gynecology and Radiotherapy units were research participants of the study. Even though I initially planned to interview only eight patients, the number of participants have been increased to 15 (12 patients and 3 key informants) due to the fact that data acquired from the interview was continued to vary and the I wanted to gather adequate and insightful information regarding the psychosocial experiences and needs of cervical cancer patients.

Sampling Technique and Participants Selection Procedure

A purposive sampling technique was used as it is pivotal to identify and include information rich cases that could provide a full sophisticated understanding of the psychosocial experiences and needs of cervical cancer patients. Spirer (1980) sates that purposeful sampling is

geared at measuring certain characteristics but also utilized to learn or understand something.

Corresponding to the aim of the research, it has attempted to explore, analyze and understand the psychosocial experiences and needs of women patients diagnosed with cervical cancer.

Inclusion and Exclusion criteria: Careful considerations have been given to the aim of the research to make decisions about the desired ranges and characteristics of participants. Women patients were included not only on the basis of their willingness to participate in the study; but participants have been included with the assumption that they were presumed to be representative to certain pre established criteria. Therefore individuals selected for the sample were women patients over the age of eighteen years, diagnosed with cervical cancer, had started treatment of the cervical cancer in Black Lion General Referral Hospital, have the ability to make conversations in Amharic language and who have the ability to contribute to the understanding of their psychosocial experiences and needs regarding the issue. Exclusion criteria for the study were difficulties to communicate in Amharic language, those who are diagnosed with other types of cancer and patients also diagnosed with cervical cancer yet developed mental illnesses.

Data Collection Techniques

Both primary and secondary techniques were used to collect and obtain relevant and basic data which is important to carry out this research. Multiple sources of evidence that is in-depth interview, key informant interview and document review were employed for this study. The rationale to use multiple sources of data was that it strengthens the trustworthiness of the data collected, as it was also suggested by Yin (2003).

In-depth Interview: I used in-depth interview as a primary tool for data collection. Yin (2003), states that interview as essential sources of information. Spierer (1989) identifies interviews as qualitative methods of data collection. Grinnell (1988), states that qualitative methods seeks the essential characters of the psychological and social phenomena via interview instruments. The emphasis is to comprehensively describe the meaning of events of individuals. In-depth interview was believed to best suite the investigation of what individual's experience is, how they experienced it in terms of the conditions, situations, or context, their attitudes and thoughts. The purpose of interview was to explore the views, experiences and needs of cervical patients and to assemble detailed descriptions of social reality. Qualitative methods, such as interviews, are believed to provide a 'deeper' understanding of social phenomena than would be obtained from purely quantitative methods, such as questionnaires (Silverman, 2000).

Unstructured interview with patients was the major techniques of data collection. Unstructured interviews are seen as purposeful discussions with the individual (Spierer, 1989). Siedman (1998) views unstructured interview as in-depth and phenomenological. The goal of unstructured interview is to extract the patient's experiences. The advantage of unstructured interviews is therefore, it will facilitate in-depth exploration. Moreover it is most appropriate where little is already known about the study phenomenon or where detailed insights are required from individual participants. It is also particularly appropriate for exploring sensitive topics, where participants may not want to talk about such issues. Yin (1989), adds that facts and opinions can be asked and explored through open interviews. Via these open interviews the psychosocial experiences of cervical patients was explored and described in detail.

Key Informant Interview: According to Grinnel (1997), multiple data sources should be used in case studies in order to attain an in depth understanding of the cases being studied. Hence, to further understand the situation and triangulate the data obtained from cervical cancer patients, Using key informant interview checklists, three health professionals which comprises of one medical doctor, nurse and other head nurse working in a gynecology ward were interviewed for this study. The professionals' views and perceptions of health workers on the cervical cancer patient's psychosocial reactions and responses during the diagnosis and in the course of treatment was better understood from data gathered using the key informant interview technique.

Document Review: The secondary data related to the topic, was obtained from different books; various magazines and works of researchers, as well as published and unpublished reports. Data from the documents were used to support and supplement evidences gathered from the field interview. More importantly, for verifying and identifying details like age, diagnosis result, treatment type, follow up, etc. of the patients; medical records of the document from Black Lion Referral Hospital was intensely reviewed for the study.

Measures taken to Improve Trustworthiness of the Data

In order to assure trustworthiness and the quality of data collected through different techniques various measures were taken. Trustworthiness is the ability of researchers to convince participants and self that the findings of the inquiry are direct, truthful, or reliable (Babbie and Mouton, 2004, P.276). Qualitative research is trustworthy when it accurately represents the experience of the study participants (Streubert and Carpenter 1999, P.333). Trustworthiness is enhanced (improved or increased in quality) by credibility, transferability and conformability (Babbie and Mouton, 2004, P.305).

According to Polit and Hungler (1997, P. 277), credibility refers to “the confidence in the truth of the data”. The truth value of this study was obtained from the experience cervical cancer patients during the diagnosis and in the course of the treatments, the research design used, method of data collection and the context in which the study was conducted. I have applied three techniques to achieve the credibility: My experience with cancer issues and terminologies which I was developed during my engagement in field practicum in the institution and in other health related courses, triangulation of data’s from different sources (secondary and primary sources) and allowed peer checking of the final result.

Transferability refers to “the extent to which the findings can be applied in other contexts or with other participants” (Babbie and Mouton, 2004, P.278). As the research is qualitative by its nature, I was not interested in the generalization of the findings. All data’s were defined in terms of the specific context in which they occurred. Conformability refers to “the degree to which the findings are the product of the focus of the inquiry and not the biases of the researcher” (Babbie and Mouton 2004:278). A conformability audit trial must ensure that conclusions, interpretations recommendations can be traced to their sources and if they are supported by the inquiry (Babbie and Mouton 2004:278). The following ensure conformability of data, when the interview is conducted, Field notes were taken furthermore the interviews were tape-recorded hence the raw data is available. By refining the data collection instrument in the course, by using codes and categorization and by developing themes from the coded data, the data’s were analyzed without my personal biases.

Ethical Considerations

In the processes of engagement in research, the researcher considered the protection of research participants by obtaining approval from institutional review boards and through voluntary written consent from participants themselves after appropriate information is given such as; “the purpose and duration of the study, procedure in the study, the right to withdraw from the study, the right to ask questions, and the potential risks and benefits of the study” (Kreuger and Neuman, 2006).

Ethical clearance to conduct this research was sought from Black Lion Referral Hospital review board. The respondents were informed in detail about the purpose of the research, interview procedures and the use tape recording during the interview. The researcher took utmost care to ensure privacy, confidentiality and anonymity of participants. To maintain confidentiality, the participants’ real name has not been used; rather pseudo names were given to participants throughout the research processes (Kreuger and Neuman, 2006). Tape recording was used only when the participants’ consent was ensured. The recorded tapes and transcriptions were kept in a locked place until the study was completed and approved by the school of social work. Besides, participants were informed that they can take a break, skip questions, and even withdraw at any time during the interview. All participants were provided with refreshment services by offering at least soft drinks and bottle of water in order to compensate for the time they spent and physical exhaustion they experienced during interview. Depending on the magnitude of financial problems patients’ are facing I was also morally forced to buy food and give money to the patients from my own pocket.

Data Analysis Procedures

Data analysis was done simultaneously with data collection since the design of the research is qualitative. To do this, in-depth interview was recorded and written down in the paper and then translated in to English. Furthermore during the interview field notes were taken concerning the participant's gestures, tones and other body languages. In doing so, I followed the thematic content method which involves transcription, translation, coding and categorization and develops themes and interpretations. According to Cough and Medill (2007) thematic analysis focuses on the coding of quality data, producing clusters of text with similar meaning often searching for the central them and capturing the essence of the phenomena under investigation.

Limitation of the Study

Limitation of the study is that other sources such as families or significant others were not straightforwardly considered during interview. An understanding of what the family or significant others experience did not gained directly from the cervical cancer patient's family. The specific area of focus was also during the diagnosis and the treatment process in the hospital not predominantly when the patients are not in their natural environment.

Chapter Four

Findings of the study

Socio Demographic Profiles of the Study Participants

A brief background sketch of study participants who volunteered to share their psychosocial experiences is presented in the table below. Note that pseudo names are given to the participants in order to assure the confidentiality as the study promised to them.

Table1: Socio demographic profiles of study participants

| Name | Age | Ethnicity | Religion | Marital status | Educational level | Occupation | Place of residence | Type of treatment Received | Condition of treatment |
|----------|-----|-----------|------------|----------------|---------------------|------------------------|--------------------|----------------------------|------------------------|
| Alem | 60 | Amhara | Orthodox | Widow | Can't read or write | Roosted barley seller | Addis Ababa | Radiation | Free |
| Adanech | 25 | Kenbata | Protestant | Single | 10 | Student | Doyogena | Chemo | Charged |
| Fikrte | 42 | Amhara | protestant | Single | 12 | Baby sitter | Addis Ababa | Chemo | Free |
| Kidist | 30 | Hadiya | protestant | Married | 12 | Evangelist | Hossana | Chemo | Charged |
| Imahoy | 38 | Oromo | Orthodox | Divorced | 3 | chef | Addis Ababa | Radiation | Charged |
| Ketemash | 26 | Amhara | Orthodox | Single | 10 | Student | Debre Brihan | Chemo | Charged |
| Maritu | 38 | Amhara | Orthodox | Married | Can't read or write | Farmer | Gojam | Chemo and radiation | Free |
| Merima | 48 | Amhara | Muslim | Married | Can't read or write | Farmer | Wello | Radiation | Charged |
| Shegitu | 35 | Oromo | protestant | Married | Degree holder | Manager | Kemisea | Chemo And radiation | Charged |
| Zenebu | 67 | Amhara | Orthodox | Widow | Can't read or write | Beverage/ Tella seller | Debrezeite | Chemo radiation | Charged |
| Zemenay | 40 | Tigrea | Orthodox | Divorced | 9 | AAU student café cook | Addiss Ababa | Surgery and Chemo | Free |
| Gemena | 58 | Amhara | Orthodox | Divorced | Can't read or write | Farmer | Gojam | Radiation | Free |

The participants of this study were women patients who are diagnosed with cervical cancer and started their treatment in Gynecology and Radiotherapy ward of Black lion referral hospital. From the total of 15 research participants in this study 13 are cervical cancer patients and 3 are health professionals who consists of one medical Doctor, nurse and one nurse head.

Regarding their ethnicity Shegitu and Imahoy are Oromo, Zemenay is Tigrea, Adanech kenbata , Kidist Hadiya the rest of seven participants are predominantly Amhara. As stated in the above table, there are three participants who are single. Shegitu, Maritu, Merima and Kidist are married and have children. Zemenay, Gemena and Imhoye have already been divorced while the other two respondents are widows. According to the data gathered through the interview, eight out of 12 are orthodox faith follower, Shegitu, Fikrte and Kidist are protestants and the remaining one (Merima) is Muslim religion follower. Educationally; Shegitu is a bachelor degree holder in management which is the highest level amongst the participants. While, Alem, Zenebu, Merima, Gemena and Martu do not write or read. The remaining six participants are between grade 1 and 12.

The participants were also engaged in different economic activities such as Alem and Zenebu used to sell Roosted Barely and Beverages respectively before their diagnosis. Fikrete was baby sitter in the school; Shegitu is still a manger in a governmental organization. Zemenay and Imahoy were chefs. Adanech and Ketemash are students while the remaining three participants used to earn money through farming activities. Concerning the place of origin of the participants, three are from Addis Ababa, Adanech and Kidst from Southern Nation Nationalities and people region (SNNPR), Zenebu and Imahoy belongs to Oromia Region and the remaining five are from Amhara region. Regarding the treatments which the participants are receiving from Black Lion Hospital, five out of 12 respondents are chemotherapy users, four are radiotherapy users. Zemenay did surgery in Black Lion Hospital and also started chemo. The remaining two participants are using chemo and radiation services from the health center. Alem, Fikrete, Maritu, and Zemenay are payment free service users in Black Lion Hospital and the remaining eight participants are paying for their perspective treatments in the Hospital.

Information and Knowledge about Cervical Cancer

Nine out of 12 participants made clear that they didn't have any information about cervical cancer before their diagnosis was revealed. However, three of the participants had information about the disease from different Mass Medias. Ketemash, Alem, Kidst, Gemena and Maritu demonstrated that, they never had heard the name cervical cancer before their diagnosis. Imahoy and Merima concluded that Cancer as evilly attack, punishment and misfortunate from God which didn't need any scientific elaboration from people. Fikrete said, "I didn't have any information about cervical cancer before my diagnosis in Black Lion Hospital. In the first place I never thought in my life that I would have a chronic disease."

Contrary to Fikrete regarding the knowledge about cervical cancer Adanech said:

The awareness about cancer was not to its great extent some years ago. However as cancer is affecting large number of people these days, having information about it wouldn't be a big deal. Peoples' awareness is also growing via Medias. They are teaching about the food habits that we should promote eating more fruits and fiber foods to protect ourselves from cancer and so on.

Zemenay also added that:

I have no obsession to seek information about cervical cancer since I never expected it would happen to me. However once up on a time before my diagnosis, I was watching a program called '*Tenawo Bebetwo*' on TV from which I heard the signs and the symptoms of cervical cancer. After some time I experienced similar symptoms in my body and started to develop some fears. Due to the continuation of this problem I went to Ethiopian Family Guidance Association for the screening test.

Shegitu also had slight information about cancer and its impacts on health before her diagnosis. However she updated herself with different information well through the internet, health related journals and magazines after her diagnosis.

Experiences towards the Diagnosis Report

According to the data gathered from the interview, though their terminology towards the event is different, all participants except one had similar experiences toward the reports of their diagnosis with cervical cancer. Adanech explained that she was traumatized and upset during the report. However she became hopeful after she is informed that cancer is curable through its treatments depending on its stage. Similarly Ketemash was also shocked during the report. However she calmed herself after she has started treatment follow-ups and recognized the improvements on her health.

Fikrte described her experiences towards the diagnosis report as a horrible and unpleasant that she wept all day alone. She said:

The doctors decided that I should have surgery as quickly as they told my diagnosis report but I was unable to pay for the surgery so that I kept searching money to borrow and started begging people for help. However no one was willing to provide me with the financial support for the surgery. Generally, I was very sad and hopeless with the result and the situation at hand.

Initially, Shegitu had been diagnosed for excessive menstruation in Desse where she is currently residing. After some medical examinations and the laboratory tests the doctors told her that there was a problem in her cervix. Shegitu described the event as follow,

I had excessive bleeding and vaginal sour, following different investigations the doctor asked me if I was able to go to Addis Ababa for better medication. Subsequently I told him that I was ready for whatever steps to take in, and then he referred me to Black Lion Hospital. However, I never had any contemplation that it would be this much horrifying disease.

Kidist and Zenebu went to different hospitals in search of solutions for their health problems before their diagnosis result is confirmed in Black Lion Hospital. Kidist said, she had countless diagnosis in Hosanna, all the doctors revealed to her was she got pancreatitis and vaginal infection. After some stages of medication there, her health did not improve. Consequently they have referred her to Butijara Hospital; in turn the Butujara hospital doctors also sent her to a private Hospital in wolyata and had a surgery there. Next to the surgery, the Doctors informed to her husband in secrete that the cancer was already distributed to her liver and referred her to Black Lion Hospital for further treatments.

Two participants Alem and Zenebu were also exercising religious rituals to bring to an end their physical sufferings before the diagnosis. Alem said, she was using and drinking Holy water without going to even nearby health centers, with the assumption that she would get better in a little while. Unfortunately her health went to the worse status. For this reason she came to Black Lion Hospital, even though the Doctors didn't told her the report in understandable manner at her first diagnosis, after some necessary diagnosis procedures she was able to find out that she had cervical cancer in its advanced stage. Similarly Zenbu also explained:

I was very sick and I had used holy water for three consecutive years without any medication. I thought it was just a simple pain. After the three year suffering my kids

persuaded and took me to Yekatit 12 hospital. Yet again I was transferred to Black Lion Hospital and heard my diagnosis result here.

Two participants associated their diagnosis report with cervical cancer as a punishment for sin and as a means to witness supernatural mercy in the course. Merima described:

All of the sudden I was confused with cervical cancer report. Cervical cancer is not a disease but it's a punishment from Allah for my sins. Allah made it my fate to be like this, I couldn't help it.

Contrary to Merima, Imahoy haven't experienced any confusions and disappointments towards her diagnosis result, since she associated it with her spiritual life styles that healing was on the way beside the report. She explained; "I didn't feel anything since I had faith that God would uproot this disease from its root. Bible says hopeless and unfaithful people are like dead ones in God's eyes."

Emotional Reactions and Responses towards Cervical Cancer: Eight out of the 12 participants reported that the experience of confusion, anxiety, fear, stress, hopelessness and strain after knowing their diagnosis with cervical cancer. Two participants were in rush for the treatments while the remaining two participants families were in much stress than the participants themselves.

Two of the participants witnessed that they have a phobia with the name cancer itself. Fikrte was totally helpless and hopeless after she heard the medical report which confirmed her diagnosis with cervical cancer. Furthermore, Imahoy explained:

To tell you the truth, the given name cancer itself doesn't give me a peace of mind and comfort. It is unpleasant word to use. When the physician informed me that I have cancer, I was shocked also my eyes were full of tears. But after some time, I critically observed in to other patients whose health condition is deteriorated and started to ask myself was I good enough for my Lord, No. The good thing is God didn't send his begotten son for saintly and wise people rather for sinners and sick people like me. No worries now, even if I am dead today.

Prior to the diagnosis result, Maritu and Alem had developed a diminutive of self worth and a feeling of despair towards their future. Maritu and Alem said they were upset with the report; in addition it aggravated their pain. The disease also forced Maritu to give up all the things that she worked for. However she admitted that the treatments gave her some hope and relief to her illness.

Some of the participants also felt that they were facing with the realities of death after their diagnosis report. Adanech who is age 25 explained:

I was very sad as cancer is a fatal disease, though death is for all, in my age it is difficult for me to welcome it. However after all this my Pastor told me that, I should be thankful for everything and the outcomes of obsessions and stress was another disease by itself. Since then I have started living my life with hope.

In the contrary Alem whose age is 60, stated:

I always have an awful night mares. All my aim after the diagnosis with the cervical cancer is to die soon so that the disease wouldn't put me to the worse situation. It is even

worse now. I couldn't feel any hope or good life for my future. At this time, all I am seeing is death knocking the door of my life.

Zemenay did not expect that she would live this much longer. She said, in the past tough days, she was controlled by a bizarre feeling that she cried day and night for at least 15 successive days after her diagnosis with cervical cancer. In the midst of this she heard her younger brother death in a car accident as he was coming to Addis to visit her. The incidence worsened her grief. On the other hand, Kidst said:

Of course my husband was so much in hurt when the Doctor told him my status. He continued to cry thinking that our kids would be lonely and motherless. However I kept telling him that there was always a victory after war, I guaranteed him as God is great worrier, so as to help him forget all the miseries that we were facing.

Likewise to Kidist, Shegitu was also able to control her feelings towards cervical cancer diagnosis. However, her husband and sister were more anxious about it. Shegitu's husband wasn't aware what the diagnosis reports were. However, after she has started her treatments, one day, the doctor talked about cancer in front of her husband and sister, which was she said a shocking experience to her husband. In addition, Zenebu pointed out that she didn't care about the medical report; all she need was to find the treatments so that she would get relief for her pain.

Interpersonal Relationships and Concerns of Intimacy after the Diagnosis: Eight out of the 12 participants reported that their relationships with relatives, coworkers, families and friends are affected by cervical cancer. On the other hand the remaining four participants revealed that they maintained their relationships successfully as before.

Alem who is 60 years old, demonstrated her relationship as extremely as disgraceful given that she doesn't have a family or any relatives except her cousin. She said, her son whom she raised by selling Injera and washing people's cloth died 14 years ago, since then she couldn't have any contact with her neighbors. She gave details as follow,

...I am all by myself struggling to survive. I don't have anyone who says sit here, eat this, leave that, take your medication or have some rest. No one is around me. The only cousin whom I would call for a help is not anymore willing to live or suffer with me. It has already been two month since he left my home.

Nevertheless Zenebu and Alem are almost having similar age, contrarily to Alem, Zenebu viewed her relations with other people as rewarding. She explained:

Thanks to Lord, I have good quality of relationships with everyone. Friends and neighbors are visiting me more frequently after my diagnosis. Look at me (to the researcher) I am old but I have also a very old mother who is living with me who took care of me like a baby. My kids are also very loving and caring.

Similarly to Zenebu, Imhaoye also reported that she has good interpersonal relationships and communications with people as before. She also revealed that, even though she has rejected some of her old friends who were leading their lives contrary to her beliefs and life styles, all families and friends were beside her during her diagnosis and in the course of treatments.

Shegitu and Fikrete demonstrated that, their connection with people destabilized following to the diagnosis. Fikrete said:

I moved to my aunt's house after my diagnosis. However I don't have sound relations with all my relatives, since we follow different faith. Even when I was admitted to Black Lion Hospital, I never had a friend or relatives near to me to take care of me rather other patient's family were helping me.

In the same way Shegitu explained that, some of the people who were very close turned their backs on her after the diagnosis. Though her friends from office were supportive in the critical time, her relatives didn't get nearer to her. She also suffered a lot seeing that she couldn't find someone who looks after her kid when she comes to Addis for the medication. Adanech and Kidst couldn't have liveliness to go and visit their friends as previous days; however their friends and kin's visit them periodically. Maritu and Zemanay also reported that without the provision their friends and families assistance, support, prayer and care that they wouldn't stay longer. On the other hand, Merima who had started her treatments three month ago in Addis and whose families and friends are not yet aware of her diagnosis with cervical cancer, could not describe what her future would embrace with the people she knows.

Role Performance after the Diagnosis: All participants explained that their roles both at work place and home have been totally shifted into different dimensions after their diagnosis with cervical cancer. Zenbu, Fikrte, Zemenay and Alem described that, they have resigned from their jobs due to their dire health conditions after the diagnosis. Alem said, before her diagnosis she used to earn money by selling roasted barley and nuts in the streets sometimes in *Shuro Meda* market which used to help her to cover daily consistent expenses. In addition she used to save money through *Iqub* (traditional money saving system) and furnish her small *Kebele* house. But now due to her sickness she couldn't do it anymore and it is unthinkable to have her job back. Similarly Zenebu, who also raised her nine children by selling a traditional beverage

(Tela) explained, “I am no longer selling *Tela* after my illness with cervical cancer. I am hopeless about my jobs. These days all my aspirations are to get well and go to the churches and attend the rituals.”

Imahoy who had also worked in different hotels as a cook, explained that, her colleagues used to appreciate for the courage’s and commitments that she had in work place. However, it has been almost three years since she recognized her diagnosis with cervical cancer and stopped her job. Now a day her job is traveling to different churches for prayer and deliverance. Zemenay, due to her illness, who resigned from her job six month ago explained:

It has been six month since I quitted my job. Even though when I got better I try to do some house chores like coffee preparation, this disease severely affected my life. Everything is difficult to me. I couldn’t help my only daughter as she deserves.

Fikrte whose regular job was a baby sitter in schools, could not do it any longer, due to her chronic illness. She explained:

When I feel a little bit fine I can cook my own food and wash a dish. However I can’t do my job. After some cycle of chemo I was totally fine and thought that the cancer left my body. Then I had started my old job all over again. However, when I was on the track, to take my one month salary that the initial signs and symptoms of the disease started again. Since then I never wanted plus couldn’t have the supremacy to do my job once more.

Shegitu who is a manager in local governmental institution, has stated that, not only the cancer affected her role and responsibilities but the chemo treatments also did. She explained:

When I went through the chemotherapy treatments, I might be sick for more than fifteen days. Due to this I can't go to the field trips. And after my diagnosis I never went to the wedding party ever. I am telling you (to the researcher), this disease has already destroyed my professional life. I have the knowledge and the skills however; I could not accomplish my responsibilities due to this illness. I would have been promoted to the higher position by now but this disease couldn't let me go. The staffs couldn't trust my condition; they think even if I am given the opportunity, I would die in the mean time.

Maritu, Merima and Kidist also pointed out that the cancer affected their movements to other place and their function of raising children at home. Maritu complained:

This disease is like a curse. Leave the children; I can't even feed myself. I got seven kids (3 boys and 4 girls). I didn't educate them. I and my husband forced them to be just hard working farmers like us. My girls are not grown up yet; they don't have any idea on how to prepare food. Pity for my kids, I couldn't help them all I am doing is eating what is given to me. I have so many regressions about my life after the diagnosis.

Merima also couldn't perform her maternal responsibilities after her diagnosis with cervical cancer. She said, she got exhausted and could not be able to see after her children while traveling from Wolo to Addis for her medications. Moreover Gemena who is mother of eight children stated that she left home and her children in order to have her medication in Addis two years ago. She said, let alone work, she couldn't stand or sit properly since her diagnosis; days and night are similar to her. She only moves when she wants to go to the bathroom and to the hospital. In addition she said, her children's call her frequently to tell that they are hungry and that there is no food in the house but she couldn't go to them since she is here for the medication.

In the same way Kidist also stated that the disease corrupted her house chore abilities. In addition she couldn't walk to far places on her foot for evangelical missionary purposes in the vein of the old days after she had diagnosed with cervical cancer.

Ketemash and Adanech, who were grade ten students before their diagnosis, could not continue their education. Ketemash reported, though being at her young age her life styles and things she does is somehow affected by cervical cancer, she is doing better as compared to other participants. Contrary to Ketemash, Adanech explained:

Previously before my diagnosis, I wouldn't choose between things that should be done at home. I used to do any job be it male or female type. These days, I couldn't help my mother as old days. Though I tried to help her I get sick subsequent to it. I also give up my education due to my illness and the distance of hospital from my locality. I gave up on it, the main thing is being healthy otherwise everything is useless.

Sexual Life after the Diagnosis of Cervical Cancer: Five out of 12 research participants who are widows and divorcees, as the topic is sensitive for the Ethiopian culture and due to personal reasons refused to discuss issues related to their sexual life after the diagnosis. However three participants clearly stated that they have faced problems in their sex life due to their diagnosis with cervical cancer and its treatments. On the other hand, one participant stated that even though, she tried to satisfy her husband, she has faced physical fatigue during sexual intercourse after the diagnosis. The rest three single participants stated that they are not concerned to any further extent to think about sex or marital life.

Merima explained that, since her husband has another wife, he could not be pleased to have sex with her following to her sickness. She explained:

Though I was the first wife for my husband, he was married to second wife last year. I and my husband sleep in separate beds, from the time when I was sick with the cancer and start the treatments which made me physically dead.

Similar to Merima, Shegitu and Maritu also described that they couldn't have capability and desire to have sex with their husband due to the side effects of cancer treatments on their sexual urge. Moreover, they reported that their husbands also didn't insist them to have sex or any romantic time together after their illness with cervical cancer. Shegitu explained:

Well it has been almost a year since we stopped having sex. You know (to the researcher) my doctors suggested that we can have sex whenever we want depending on my health condition and use family planning, one day I also directed my husband to have sex with me however, he said that I shouldn't be bother about this things. That sex is minor thing. All my husband need is seeing me be healthy and part of the family again.

Imahoy who is a divorcee described sexual intercourse as nonsense and irrelevant for her life. She said, "God prohibited me from having such a rubbish desire long time ago. Why should I bother to satisfy someone? These days, all my ambitions are to get healed and lead my normal life."

Experiences of Patients to the Treatments

Regarding the treatments, five out of 12 participants are chemotherapy users, four are radiotherapy users. One participant had surgery in black Lion Hospital and also started chemo there. The remaining two participants are using chemo and radiation services from the health center.

According to the participant's reply, despite the fact that the side effects of the treatments are very complex for management, nine participants agreed that their health have improved after they have started the treatments.

Adanech who is a 6th cycle of chemotherapy user in Black Lion Hospital explained that, after she has started treatment she began to experience physical fatigue, headache, nausea, vomiting, and diarrhea and hair loss. However she didn't hide that she got some hope and guarantee on her medication. In addition she told her current situation is better than the previous one, that her food appetite is getting better after 15 days chemotherapy plus her excretion systems started to function well. Furthermore, Fikrte who is a chemotherapy user stated that, before her diagnosis with cervical cancer she had bleedings, vaginal discharge, back pain and skin rash. Subsequent to her treatment she also faced hair loss, vomiting, fatigues and exhaustions. Besides Fikrte explained, after some cycle of chemo treatments even though there was substantial improvement in her health, this days the initial signs and symptoms started to occur again. She said, the doctors told her that the cancer is not responding to the chemo treatments any longer, so that they would prescribe her with radiation on her next session.

Zenebu Kidist, Ketemash and Maritu similarly stated that, bleeding ,vaginal discharge, urine and defection problem, back pain and physical weakness were the signs and the symptoms that they have experienced before the diagnosis. But in the course of their chemotherapy treatments, they also faced health troubles like diarrhea, vomiting, and low appetite, loss of hair and stomach disorder in the treatment phases. Regarding the effects of the treatments on long term qualities of life, Zenebu reported that:

Somehow nowadays I can urinate, but the treatments are very tough and it makes me exceedingly weak. Following to the treatments, when I stand for a minute my legs start to shak. The doctors suggested me to drink soft drinks but the treatments couldn't allow me to taste such stuffs. Whenever I taste something it comes out right away. This is not a disease it is a curse.

On the other hand, Maritu, who have taken only one cycle chemo, explained that:

Whether it cures or kills me, I am taking the chemo. When I started taking chemo my hairs fall down. I don't care about my hairs or physical appearance any more, all I need is to be cured from this disease. There is also a huge improvement ever since I have started taking chemo. I can walk by myself now. If I were not started taking the chemo I would have been dead by now.

In the same way to Maritu, Kidist also stated:

Of course chemo has got terrible side effects like physical exhaustion, vomiting, loss of appetite and hair loss. However my aim is to get well, so that, I am defending the side effects through prayers and by taking different measurements. For instance when I took chemo my appetites gets down to zero. However I always try to taste some food so that I can maintain my weak spot. The qualities of life which I have after the treatments are, now I can walk, sit and stand. I also can talk with the people for long time as the old days. My health improved a lot after starting the treatments.

Merima, Gemena, Alem and Imhoy who gone through Radiotherapy treatments reported that they have experienced Vaginal pain, skin rash and discoloration, Blackish Diarrhea, vaginal

irritation during their radio treatments. However, except Gemena, others witnessed that their health improved a lot subsequent to the treatment. Imahoy explained:

It's 13th cycle of Radiotherapy which I am taking now. I have pain inside my vagina, I also have blackish diarrhea, skin rash regularly after the radio treatments. However thank God the side effects would not stay longer with me , even if it does, I can compromise it hence my objectives are to get heal and to be cured. Moreover my health improvements out way these disruptions. Excessive bleeding and vaginal discharge has already gone through this medication. If I dint have an opportunity to follow this medication I would have been dead already.

Following the needed testes and medical examinations in Black Lion Hospital, Merima also, started Radiotherapy treatment three month ago. She explained, "I had vaginal discharge with bad odor, continuous flow of blood, back tenderness, physical weakness, sour mouth and lips before my diagnosis. But after the treatments, I can sit properly, I can also move by myself."

Alem reported that she got energy at least to wash her clothes and prepare her own food after she has started radiotherapy treatments, however, she explained during the treatment sessions she faced physical fatigue, vaginal pain and irritation.

Shegitu on the other hand, who have taken nine rounds of radiation and eight cycles of chemo, stated that, she has experienced different incidences on it. She said:

I have already taken nine series of Radiotherapy and waiting also for the 9th cycle chemo. Radiotherapy physical difficulties are that my skin has changed its colors; my vagina itches and irritates me very badly. While using chemo I lost my hair, my lips are injured, I have fever and headache constantly, my food appetites are also gone. On other hand the

treatments have helped to improve my health a lot. Though I am not recovered fully I am doing well currently.

The first treatment that Zemenay got from Black Lion Hospital was surgery and then the doctors ordered her to start chemo. She has already taken six cycles of chemo so far. She explained her experiences as follows:

I have prolonged vomit and high level of constipation; I am not comfortable with food taste or odour. I also hate noise, subsequent to chemotherapy treatments I would be happy if no one is around me to push me talk. Regarding the long term quality of life that I have now is wonderful. I feel like I am resurrecting from death because of these treatments. No need to go further, it is enough to look for the reason why I walk up right now.

Gemena on the other hand who took 14 cycles of radiotherapy, however the cancer stops responding to the treatments, regretted her being in the hospital and taking the treatments for no enhancement or relief for her pain. She explained:

In addition to Radiotherapy, there is also Morphine (Pills) that I am given for the pain. These treatments are like a flame for me. When receiving Radiotherapy, my whole body burns, I feel dizzy, constipated, nauseated and have diarrhea in regular base. For about six months I was okay. However, back then the original signs and symptoms have started again, it is even worse. I can't control my pees. The doctors told me just I need to go to home and wait the death. If I had gone to the holy water, I would have either died or curried by now.

Life Management after the Recognition of Diagnosis Result and in the Treatments Phases

Six out of 12 participants reported that as quickly as they had recognized their diagnosis with cervical cancer directly considered the use of treatment as a major solution for their health problems. Despite the fact that the rest of six patients explained that in addition to the treatments they have managed their sickness by enchanting different measures and activities like through the discharge of their emotions for the diagnosis result such as by crying, by taking advices and guidance from religious leaders and health professionals. Moreover the participants added that through prolonged social support from the families and friends and by the use of holly water and prayer that they managed their lives after the recognition of their lives.

Alem reported that she washes her pubic areas with cold water four times in a day in order to get relief to her pain at least temporarily. She also explained:

It has been almost a year since this disease started disturbing my life. Even though, the doctors recently told me that the cancer is distributed to other parts of my body, I am still requesting God's forgiveness and favor to free my flesh from this curse. It is degusting to talk, while my woman body irritates me, I use cold water to wash it and it helps me as a pain killer for the time being. In addition I went to the church regularly to take holly water. Nevertheless I can't cover up that sometimes I also feel that I don't have any hopes for my health conditions.

Similarly to Alem, Gemena also stated that, first she went to the holy water, and then she came straight from Debre Markos to Addis Ababa in order to start her medication. She said, she came one week before New Year thinking that she would return back to her eight children right away. However she stayed for two years in Addis with her sister without meeting her children in

order to obtain radiotherapy treatments from Black Lion Hospital. She said, she takes morphine every four hour to deal with pains.

Zemanay, Ketemash and Adanech pointed out, following to the examination to cervical cancer their principal resolution was emotional grief. Back then they said, they have tried different approaches to deal with their lives and to the challenges they faced after the diagnosis result.

Zemenay said that, subsequent to her diagnosis report, she had dropped tears for a long time. She also described that as a result of an extensive counseling and countless support from people and her daughter's friend that she was able to control the incidence. Adanech also stated that, at first she couldn't believe her diagnosis with the cervical cancer so that she cried most of the times. However, she learned a lot about the disease and its treatments on the track and she begun to agree with the doctors decision and started the chemo. In addition she explained that she kept praying for the deliverance from cervical cancer affliction. Similarly Ketemash stated:

I thought I would be dead by that moment in time; first I grieved then went to church to confess all my sins to the priest and get baptized there. However here I am able to manage my life with the cancer through its treatments and by holly water. I also have a great faith in God that He would totally heal me from this disease. That's what they say, Christians never misplace hope.

Maritu, Imahoy, Zenebu, Merima and Shegitu reported that subsequent to their knowledge of living with cervical cancer, they immediately started the treatments for their illness. Zenebu and Imahoy also added that support from their families and friends were very

crucial other than the treatments on the progress of the recovery from their persistent infirmity.

Imahoy explained:

Primarily, I have started my medical treatment in Black Lion Hospital after that I went to the church to have holy water. On top of all, those distressful times and affliction are gone as a result my families and friends care and support continued. Unless and other wise I had already been dead three years ago. Thanks to them I am still alive. I have confidence that this time of suffering will also pass away and vanish forever.

Zenebu illustrated that, prior to the treatment which she has taken from Black Lion Hospital, social support and financial aid that she received from her elderly mother and loving children was essential for her survival. On the other hand, Merima explained that she left her home and come to Addis in rush for the medication without informing families and relatives about her health condition. Similarly Shegitu also pointed out that:

When the doctors referred me to Black Lion Hospital, in April13 last year, I came straightforwardly to Addis for further medication and treatments. That was the only step and solution which came to my mind after my recognition of cervical cancer.

Moreover Kidst reported that she considered prayer and her aunt assistance as the only means subsequent to the treatments in order to recover from her illness. She explained:

Well I manage it through continuous prayers and by the help of my aunt. She was enthusiastic to allow me to move to her house when I was in a critical situation. In my entire life I am eyewitness for God's miracles over unmanageable things. Seriously I know cancer is a killing disease however it is nothing for God. Therefore I had and still have strong faith that I would be cured from this disease by blood of Jesus.

Consultation about the Treatment Problems: Five research participants (Shegitu, Kdist, Zenebu, Gemena, Adanch and Alem) reported that they would wait their prospective check up appointment dates and treatment cycles in order to have consultation with their doctors. While two participants (Imahoy and Zemenay) illustrated that they have consulted their physicians prior to their health troubles and the side effects of the treatments. On the other hand, the three participants (Shegitu, Fikrte and Merima) explained that they wouldn't consult any one about their treatment problems apart from leading their lives through the challenges. The remaining two participants (Ketemash and Martu) pointed out that they would seek advices from their families and friends in case if the treatments wouldn't work well.

Alem who is following up her radiotherapy treatments in Black Lion Hospital, is disappointed with the doctors who are working in the ward however she don't have any other option except requesting their help during her treatments. She said:

I don't have a son, a daughter or any closer relative for whom I could let know about my illness and the treatment side effects, all I have is the doctors who are administering the treatments in a radio therapy ward. When the treatment cycle comes I would tell all the problems that I am encountering in the course of the treatment. However they wouldn't give their ears for the problems I am talking and obsessing. All they do is do the talk in favor of them and just prescribe the treatment.

Similarly to Alem, Fikrete also stated that she would be worrywart to have some professional advices from the doctors due to the fact the information they provide make her to have dilemma about her health conditions and the treatments in general. She said:

I have no one who could give me some advice about my health situations and the treatments. I would rather die than coming to the doctors to talk to about my problems, since there are new doctors from time to time. Every time when I come for the treatments the doctors would tell me very bad things. In addition when one doctor orders something the other doctor will argue and change it. In the mean time I am getting very sick, that's why I am no longer concerned to have their valueless advice however I would ask Lord's intervention in everything.

Shegitu pointed that, at the same time as the Hospital location is distant from her area of residence, she couldn't have a regular likelihood to have advices from the doctors or other health professionals working in Black Lion Hospital regarding the treatment problems. Furthermore, Zenebu and Kidst said that in case if they seek any professional advices from their doctors, they would hang around for the appointment days and share updates and the drawbacks of the last session treatments. Gemena who is payment free treatment user in Black Lion Hospital Radiotherapy ward, affirmed that from time to time when she gets ill and when the treatments doesn't work that she comes to Radiotherapy ward and tell her problems to the doctor. However she complained about for long line of waits and the number of appointments that she could have in order to meet the doctors.

On the other hand Imahoy who pays for the treatments and other services in Radiotherapy ward stated that, since she lives in Addis if there are no any health improvements in the course of the treatments, she reported that she would come directly whenever she wants. She also said the doctors are cooperative whenever she comes to visit them. Moreover Zemenay who was a staff member of AAU medical school before her diagnosis reported that being the member of the staffs give her advantages a lot to have a good dealing with all staff members

starting from the sanitary workers in the course of the treatments. She said when she faces some problems in the prescription of the treatments, she would consult physicians in addition sanitary workers provide her with the extra food and milk. Nevertheless Adanech explained:

At my region there is no one to discuss about the treatment problems. However at Black Lion Hospital, they give me appointment for chemotherapy every 21 days. Sometimes they may come up with the reason of shortage of beds for admission. But the doctors are willing to talk to me if there is any improvement in my health or problem concerning the treatments. The doctors working in a gynecology ward are really very kind.

Ketemash reported that she consult her parents and friends if the treatments start to disturb her health, depending on her parents advice she said , she would try other traditional treatments in addition to the former one. Furthermore Merima illustrated that she would consult her husband most often if she got problems with the treatments.

Participation in Religious Activities and other Voluntary Groups : Though their contribution in other social affairs are very deprived following to their diagnosis with cervical cancer, almost all participants pointed out that their participation in religious activities augmented bearing in mind that they would discover divine intervention for their illness. Seven participants reported that they went to the Orthodox Church regularly to find holy water forget their misery. One participant who is Muslim religion follower also told that she went most often to the mosques and she also participated in other social affairs to. Moreover the other three participants reported that they have strong fellowship with their prospective church members in addition to their partaking in a prayer lines and other church service. However, the remaining one participant reported that she was completely distance away from the church and prayer

services after her diagnosis however she was insisted to turn by her Christian friends from the church.

Imahoy explained:

Though I am not active participant in any voluntary group except singing group, my affection and dedications to my faith and members of the church have already increased after my diagnosis. When God punishes you, your hurt gets break down plus you wouldn't know what to do afterwards. Following to my diagnosis, I wouldn't mind if it is a day or night, I was just traveling from one church to another in addition to different monasteries in all sides of the country. I also drink holy water often to bring back my health and to transform my wicked spirit. Though I couldn't resist the pain over my flesh, now I have adjusted myself well to the Lords agenda and made all my confessions already. I am not petrified to death anymore.

Furthermore Shegitu also stated that religious activities played a great role in her life.

Besides she stated that, her sustained prayers were an answer for everything. She affirmed that:

I attend church services every Sunday. Spiritual life is an awesome weapon to defeat evil spirits. Prayer is more than medication to heal cancer as well. I always pray day and night. My Christian friends also cried before God about me. God heard their prayer and helped me to live till now. There is one poor woman in the bible that she was bleeding like me. However hers was for consecutive 12 years. One day Jesus was passing and then she believed that she would be healed if she even touches his dress in the crowd. When she does that her blood stopped immediately. I also have faith that when my turn comes

God would deliver me totally without any scratch. That's why I kept knocking his door since the time of my diagnosis report.

Similarly Kidst who is evangelist in her calling in the church stated that, even though her participation in church affairs and other social events like in wedding and mourning has reduced after her illness. She reported that her faith become stronger after her diagnosis, she also organized a prayer service inside her residence with the neighbors to pray for cancer patients and to have worship together with other people in a daily basis. In addition she stated that she have a strong faith for her healing very soon and she reported that if her Lords grace was devoid of her, she would have been dead long ago before her diagnosis. Contrary to Shegitu, Fikrete stopped up praying and attending church programs when she heard that she got cervical cancer. However after sometime through her fellow Christian members and pastors' prayer and well-built guidance she was able to return to her ordinary spiritual life. She said though pastors and elderly people couldn't come to her house for prayer she reported that they would pray for her via phone calls. At this instant she give up everything on earth so that she explained that even if she dies due to this illness, she would have a better place to stay within peace in the company of her heavenly father. On the other hand, ketemash stated that her friends from the church come to her house to accompany her and also insist her to take holy water. Though she said, she couldn't go to the church, she prays to God to make this chemotherapy her end. In addition; she uses holy water day and night. Zenebu also explained:

I always pray to my health problems seeking solutions from God. I also never taste a food without drinking holy water. When I am admitted to Black Lion Hospital, I took holy water with me. However, this sickness couldn't allow me to go to the church and to participate in other social affairs as before.

Zemenay also stated that she watches spiritual movies and songs with her daughter and her friends in the house most frequently. In addition to the medical treatments, her daughter brings her holy water. Maritu has been in Addis for her medication since last three months stated that, she went to the church most of the time to take holy water and to pass the time till her appointments are all set in the hospital. She also affirmed that even though she is reluctant what might happen about tomorrow, before her diagnosis, she was an active participant in wedding, *mahiber* (religious feast), *iddir* and so on. She said, she prays to be connected to the real healing and to see her children without fever. On the other hand Gemena stated that:

I used to drink “tsiwa” (gatherings in the name of saints) with a group of religious women but it has been two years since I have done that. I was part of “iddir” (an association for mourning services) however, I don’t know if the children are still paying. After I came to Addis, I used to go to the holy water. However the coldness of the water makes my body so tense. When it touches me my body gets worse. I hoped the medication would cure me but it didn’t work. Now it’s done. I am going to die.

Merima stated that she went to mosque most of the time respect all Muslim prayer times. She said, though death is inevitable she keeps praying to be able to raise her children. On the other hand, Adanech explained that she always goes down on her knees cry and pray to God to have his mercy and deliverance. Though she doesn’t usually go to the church due to her illness, people from the church and those who serve in the church come to her home pray for her and minister the word of God.

Needs of Cervical Cancer Patients

Lack of screening services in Local areas: Except four participants (Imahoy, Zemenay, Alem, Fikrte) who are living in Addis Ababa, the other eight participants who come from regions reported that there is no a quality of screening services for cervical cancer in their prospective localities. Kidist went to various hospitals in her region; she said she was in three different towns namely Hosana, Butjira, Sodo before she had made a diagnosis in Addis Ababa. Ketemash, Zenebu, Adanech, Maritu , Merima and Shegitu also explained that even though they had gone to different hospitals in their origin however they never heard any health issues related to cancer in those hospitals. However they were referred to Addis Ababa for different reasons. They also pointed out that, there is no any hospital in their regions functioning for cancer screening service except very little unknown private hospitals. Gemena said:

It has been two years since my sickness started. When I went to the local health center after taking my two hundred birr, the doctor wrote me a referral to Debre Markos hospital. When I came to Debre Markos with my brother, they used to give me pills which didn't improve my health. They kept me hanging for a year before they referred me to Black Lion Hospital.

Zenebu similarly illustrated that, even though she went to different hospital in Debrezeit, before her diagnosis in Black Lion, she never has been told that her illness was allied to cancer. She said all the doctors said to her were vaginal infection and kidney complication.

Issues Related to the Treatment Services and Location: Ten out of 12 participants reported that they have faced different challenges in relation to the health care service provision in Black Lion Hospital. shortage of bed for admission, number of lengthy appointments per one

cycle of treatments, continuation of pervasive transparency problem in a liaison office, expensiveness of the treatments, shortage of medical equipments so that most of the time the patients are obligated to make laboratory tests and other investigations in a private hospitals, poor communications and unfair treatments among the health professionals and distant of the treatment services are the major challenges that the participants pointed out during the interview.

Ketemash who have taken six cycles of chemo as an outpatient in Black Lion Hospital explained that, getting bed for admission is the main problem. Though she waited for her turn in liaison office for many days, despite of her turn they left her and gave the chance for others who are suspected to be relatives of some staff members in the Hospital. She also added, since she doesn't have relatives in Addis Ababa, if she affords it, she might stay in the hotel but most of the time she is forced to sleep in the hospital compound till bed for admission is available due to her financial problems. Furthermore she stated that there is also poor communication among the doctors. She said in her 6th cycle of chemo session the internist Doctor prescribed her a wrong drug when she brings it, she was told by the senior specialist it was wrong. But it cost her 4500 Ethiopian birr. She said, she cried a lot tried to sell it but, any one couldn't buy it from her. And she was also expected to buy the right drug which was for more than 3000 birr. Similarly, Zenebu, Adanech, Maritu and Kidist also stated that insufficiency of beds and unavailability and high expenses of the treatments are the challenges in the course of their treatments so far. Zenebu said, due to the financial crisis she is facing, she went to *kebele* to request a letter of cooperation for free treatment. However she was rejected. On the other hand, Adanech explained she was told to change the type of chemo she used to take in her 6th cycle however she couldn't find the exact prescribed chemo so that she is forced to take another brand of medicine.

In addition Alem clarified that, though she brought a free service card to Black Lion Hospital she didn't start the treatments as she planned, she also blamed doctors for not understanding her problem plus they ordered her to other private hospitals which have business links with them to examine her laboratory tests. However she pointed that except the shortage of beds and number of appointments, the treatment location is convenient to her place residence. Fikrite also reported that most of the doctors run their business in well paid private hospitals for this reason they couldn't be able to provide services in Black Lion Hospital as expected. Just the names of the doctors are posted on the side of their office desk however they are absent from the work most often, so that the patients are forced to have a number of appointments to reach to the doctors. Similarly Gemena after 1 years of radiotherapy who is suffering from the remission of illness and who is totally dissatisfied with the service demonstrated that:

I have given up my house, my marriage, my children and came here for the treatments. However, after 11 rounds of radiotherapy, the doctors said that the disease had already spread all over my body so that they couldn't do anything. There is a problem till we reach to the doctors, the doctors never come to work on time as well; their conversation with me is not good. They treat people like garbage. From this I prefer the health care facilities in my locality but there is no such service there. Our peoples are dying when a woman comes from one of the regions, she is asked to come after a week, a month or a six month sometimes. Women are dying. Women who have started radiation with me are not here now, they died. Problems in the areas of health care are related to corruption. The waiting times are shortened if you are a relative of any staff in the hospital. There is no transparency. Those who have money pay and get the treatments right away, while those with no money are asked to wait for six months. What is the government doing?

In the same way Shegitu also stated that, there are insufficient beds for patients in the Hospital and most of the drugs are not available in the Hospital's pharmacy so that she is forced to waste her energy and time searching medicine in the City. Furthermore, she explained that in order to take a one cycle of chemo which should be taken in every 3 weeks, she is obliged to wait for three month. She criticize that while she was waiting for one cycle of chemo others took 3cycles of chemo in unjust way. She said, that there is also issues of transparency in the liaison office to distribute the existing few beds fairly to the patients.

Contrarily to the above, three participants namely Imahoy, Zemnay and Merima, one staff member and the remaining two who are charged for the services agreed on the quality of treatment services and the convenience of the hospital location for them. However, they have mentioned that there are some gaps in the areas of doctor to patient relations.

Financial Crisis after the Diagnosis with Cervical Cancer: All participants reported that they face financial problems during the diagnosis and in the course of the treatments. Shegitu, Maritu, Kidst, Gemena and Adanech reported that they sold their belongings, oxen, sheep's and their parent's crop and land and borrow money from bank to have their medication. Shegitu explained:

One cycle of chemo costs 6000 birr, most of the treatments are not found in Black Lion Hospital. We borrowed a lot of money from the Banks. I have spent more than 70,000 birr in my medication so far. I go and come back every three weeks from Kemisea, the transportation is so expensive. Food and shelter is also unavoidable till I get the bed for admission. Due to this cost I come to the hospital by myself if the expense is multiplied by two, my kids couldn't have a food.

Maritu also stated that there is a financial crisis in her marriage because her husband couldn't harvest the crops. She said that her parents and siblings gave her 14,000 birr by selling their crop products; with this she covered expenses of her food, transportation, house rent and other medication. Kidist also stated that cervical cancer affected her families finance very badly. She had sold 10 oxen and 5 sheep and her husband borrowed from the church and his friends to have her medication in Black Lion Hospital. Furthermore she stated that her husband who is a civil servant, his salary couldn't cover the family expenses any more. Adanch also explained that, she has such a financial problem after her diagnosis so that her father sold his land and other properties to help her to follow her medication. Moreover Ketemash confirmed that:

There is a big financial crisis in my family after my diagnosis, transportation requires large amount of money, and not only is the health service costly but also difficult to afford it. I got no relatives in this town to stay with till I got the bed in Black Lion Hospital. I have spent around 50,000 birr; a single phase of chemo requires more than 3000 birr. I think the therapy should be at least available at a regional level. Getting a room at hotel, paying for food, for drugs it's so difficult and is beyond it can be said.

Gemena also stated that, she came to Addis after selling her belongings and cows for 6000. She said that the cash is ended now, she paid her some cycle of treatment bills and her sister managed other living expenses. Fikrete also demonstrated that though she is free service user, she has paid more than 11,000 birr for different kinds of examinations and treatments by requesting her relatives to support her. Similarly Zenebu reported that due to the fact that her children are facing financial crisis after her diagnosis and in the course of the treatments, she went to *kebele* to request to issue her with a letter of free medical support so that she can receive free medical treatment in Black Lion Hospital. Correspondingly Zemenay, who is a free service

user in Black Lion Hospital, also explained that she spent more than 10,000 birr in the course of the treatments. Since her daughter couldn't handle the burden, she stopped her college education and searching a job to help her mother to survive. On the other hand Merima has started her treatment only three month ago reported that she hasn't faced any financial problems so far. Contrarily to Merima, Imahoy pointed out that, even though her treatment costs were fully covered by her older brother and family members, she is disappointed for being dependent on others and for not being able to help her older mother.

Issues of Satisfaction with the Existing Social Support System: intimacy issues after the diagnosis with cervical cancer and in the course of their treatments.

Shegitu and Fikrte explained that their families and relatives ignored them in this critical state. Fikrte explained that:

When I am admitted to Black Lion Hospitals I dint have any families who could take care of me. I was all alone by myself. It is long time ago I lost satisfaction and joy from my families support. Though, I have started living with my aunt after my diagnosis but starting from the facial gesture there is always differentiation between urban people and rural. My parents live in a country side; they heard my diagnosis report but never came to check on me.

Alem also reported that, she does not have any family or relatives in order to support her in this time. She said that, the only cousin that she got and considered and loved like her own son left her house after her diagnosis with cervical cancer. She demonstrated that:

There is no one who could give me a bunch of bread or a glass of water when I am in a sick bed. I thought it was good to have someone my own blood and flesh at least to be

said ‘Alem got a relative.’ My cousin was living with me for a long time. Of course he had also paid some bills for my medication. But after sometime he left without saying a word good bye and in the mean time he sent a message saying that he got married. I would be the happiest woman if he takes his wife to my house, if it is for a real, when they go to work, I would have clean the house, prepare some foods, wash dishes and wait till they come from work. In that way I would have the opportunity to enjoy family time in this critical time. However he is not willing to come to my house.

On the other hand Gemena who is a mother of eight children stated that, leaving her loving children she stayed with her sister in Addis for two years. She is separated from families and other social support groups due to her medication. Her sister is going in tough situation living her kids and her job, she is taking care of her without having any help from other family members who are living in a rural areas. Furthermore, Zemenay stated that her merely daughter is a source of social support behind her friends from work place. She reported that her parents died long ago. While her brother died in a car crash after her diagnosis with cervical cancer. Adanech also pointed out that she couldn’t hang out with her school friends as before due to her illness. On the other hand the rest of six participants namely Imahoy, Maritu, Merima, Kidist Zenebu, Ketemash reported that they are contented with the social and moral support they are receiving from families’ friends and other religious and work groups. Zenebu stated that her kids and her mother are very supportive and caring apart from their poverty status. In addition Imahoy also reported that, though she despised herself for being a mere recipient of support without giving back anything, she said most of the families and her friends did all the necessary things for her hence she is thankful for everything. Merima and Ketemash also stated that their families

did the best they could during their diagnosis and in the course of their treatment starting from simple financial aid to other honorable psychosocial support.

Future plans of Patients with Regard to Connecting with the Family, the Community and their Treatment Follow-Ups

All most all participants stated that hopefully if they got well, would participate in their family life, the church and follow their treatments till the last minute of their lives. On the other hand three participants are hesitated for what might happen in their future. Shegitu stated that:

God has a day to save and free me from this disease. Those dark days will be forgotten. Cancer won't be added to my name and my identity. I will be cured. After I am cured, I have a plan to raise children, to be a good mom, and to raise my grand children's also. I didn't finish the race that God has started in my life. I will also forgive my relatives and serve my lord for the rest of my life.

On the other hand, Alem stated that:

My dream is disgusting and faulty. Before my diagnosis I saw a dream while my new dress was getting burnt and changing in to ash. After one month when I went to the hospital they told me that I have cervical cancer in its late stage. Since then I don't see anything good about future except death. My guts tell me that I couldn't survive from this disease hence I already opened my heart and my door to death long ago following to my diagnosis.

Similarly Imahoy also stated that she doesn't have any plans for the future. As she said, tomorrow doesn't belong to her. However, she affirmed that she would follow up her treatments in the hospital following to drinking holy water and going to the church. Zenebu also reported

that, though she don't have any tangible asset or heritance for her children's, she said all she have is her Christian cross and wordy blessing in addition she added that she doesn't have any plans except a wish that she would be fine soon and live with her children as before.

Merima, Zemenay, Kidist, and Maritu also stated that if they get well, they would probably raise and educate their children moreover want to see their grand children and would participate in religious and other social events. Maritu said: If I am healed I am going to arrange feast and prepare a wedding party for my oldest son. The little ones I am going to put them in the school. After I came to Addis seeing the doctors and nurses wearing a white gown having a commitment to help people like me put in a regression about my children's future life.

Adanech and Ketemesh also stated that, if their end is for good, if they are healed totally, they planned to repay to their family for every single good thing they have done in their lives. Moreover they have stated that until they are told it's enough, they will continue their follow up's in the hospital. Fikrte also stated:

If I am survived from this cancer, I want to worship and follow Jesus for the rest of my life. I will also follow all my treatments in Black Lion Hospital till I got healed. About associations I don't have any relations except I worship God with my Christian brothers and sisters in the church.

Findings from Health Professional Workers

Three key informants doctor, head nurse and nurse were invited to discuss some of the issues related to the service provision in Black Lon Hospital with the aim of cross checking participants answer with the health professional's observation. In this section finding which are obtained from those health workers will be presented below.

Three health professionals reported that most of cervical patients come from rural areas of the country generally from Amhara and Oromia regions. Moreover, Even though there are some patients from well to do families, health professionals reported that, cervical cancer more affects women from low socioeconomic backgrounds.

Regarding patients reaction to the diagnosis report, head nurse reported that, since there is awareness problem in their origin, when the patients are referred to Black Lion Hospital from rural areas, patients would assume that their problems are temporary genealogical sickness however when they are informed their diagnosis result is cervical cancer, they become desperate immediately and leave the examination room just crying. There is also likelihood when patients are old, that health workers are forced not to let know what their sickness is till they reach to the critical state, they are forced to tell for patients' family only. Similarly the medical doctor illustrated the situation,

From gynecological cases more than 60% counts for cervical cancer. There is only one governmental institution in Addis Ababa which provides screening service for cervical cancer but in rural areas it is totally unthinkable. There is also an awareness problem at large. Due to this as most of cervical patients are from rural areas, when we inform them their diagnosis result, they think that cancer is 100% curable and treatable.

Key informants also reported that after some cycle of treatments patients' response to the treatment vary depending on their health condition, the side effects of the treatments, knowledge and awareness about the disease. The head nurse reported that patients became more aware about their illness; the side effect of the treatments itself after some cycle of medication. Other nurse also stated, for some patients the treatments give them a greater hope to live and enjoy life

while there are also other patients who became more hopeless about their future after some cycle of medication when the side effects of the treatments became unmanageable. On the other hand, the medical doctor also explained that some patients have good attitude to the treatments however there are also some patients who stop their chemo due to its harsh effects on their quality of lives furthermore he stated that some patient's curiosity about their treatment final phase' increase as they face some health trouble in the course of the treatments.

All informants agreed that Black Lion Hospital's Involvement in community and public lives to create awareness about cancer is near to the ground. The medical doctor and the nurse explained that they are afraid to say they are involving a lot. However they sated that in urban areas, due to media publicity, when women experience some sort of bleeding and excessive vaginal discharge they went to Family Guidance Association to have a screening service. On the other hand, more than half of the patients who are from rural areas couldn't have any information about cervical cancer. Furthermore, Head nurse pointed out that:

Once there was a campaign which was organized to reach Gambela region women. Some of the staffs from Gynecology and obstetrics department went to Asosa, educated women about cancer and prepared temporary screening services and physical inspection for women living there. However I can't say a onetime event for one region is enough. There are some patients who are from rural areas who say, 'I never heard the name cancer, what is it? If the patients were well aware about causes, signs and symptoms, the prevention mechanisms of cancer, they wouldn't have stayed without diagnosis while having vaginal discharge and excessive bleeding for more than a year. Lack of information and screening service are the major obstacles for a woman to come to the hospital after the cancer is spread to all parts of her body.

According to the informants lack of resources like beds for admission, treatments for patients, unproportionality of patients and health professional, lack of consultancy and palliative care center, poor communication between the patients and health workers made services provided in Black Lion Hospital for cancer patients in general and cervical cancer patients in particular inefficient and unproductive. Head nurse explained that:

We can't say it is effective. There is insufficiency of beds for chemo radiation admission. Due to this patients are not able to follow their treatments properly. Also number of patients and health professionals are not comparable. There is scarcity of chemo for free service users in addition there is also communication problem between the health workers and cervical cancer patients. Most patients who came from rural areas do not mind about clarity of information rather they only want a relief for their pain. Sometimes they may be non-Amharic speakers, and the translator may give wrong information about their disease and the treatments. All these created biases and misunderstandings on the patients from the medical team perspectives

Furthermore, the medical doctor and the nurse also stated that, the effectiveness of information provided for the patients about cancer and its treatments would depend on the personality and maturity level of the health professionals. They pointed out that some doctors might talk to the patient in a clear manner while others may use medical jargons for those who couldn't even speak Amharic properly. Regarding the availability of consultancy services, the availability of palliative care and the participation of professionals from multidiscipline in the oncology unit, key informants pointed out that there is a huge gap.

On the topic of consultancy, the head nurse illustrated that, when the cancer gets its advance stage and stops responding to the treatments the doctors would just tell about their health conditions and provide them with pain killer called morphine and send them away to their home. She said, in case if the patients are alive, they are proposed to come to the hospital for check up in six month and a one year interval. She added that even though, once there was a mass training for oncologists working with cancer patients on how to render palliative care to patients , however its practicability is questionable . She also reported that there is only one social worker for the whole hospital whose responsibility is not beyond putting signs for free service user patients. Medical doctor also reported:

Numbers of patients are beyond the hospital capacity. I can't say there is a consultancy service in Black Lion Hospital. Even if there is by nature Ethiopians never want to hear about death. There are some patients who came from rural areas when the cancer is in stage four. We just give them a vitamin and send them home. On other hands there is also some incidences due to shortage of beds, while patients waiting for surgery admission the cancer gets its advanced state hence we change the treatments into radiation. However, while waiting to the radiation admission again the patient might even die without getting any medical help from the hospital. I never have seen any social worker in this hospital so far. There is no a palliative care center in Black Lion Hospital either.

Furthermore, key informants raised different ideas with reference to the psychosocial needs of cervical cancer patients. The medical doctor illustrated that; the patients need to be informed about cancer after the diagnosis that it is not 100% curable particularly if it is in its advanced stage. He also stated that the families shouldn't stigmatize the patients due to the vaginal discharges some cervical patients might have uncomfortable odor. Additionally he

suggested that patient's family and the health workers have a great responsibility to provide psychosocial support for patients in addition families also need to provide the patients with a good nutrition.

Similarly the head nurse stated that, firstly, during the diagnosis, there is a huge technological gap in Black Lion Hospital. Though, it's a must for patients to have CT scan and other medical tests before the diagnosis and in the course of the treatments. Unfortunately since there is no CT scan machines in the hospital. When patients are recommended to have CT scan and blood tests in other private hospitals which cost more than 3000 birr, they are forced to return back to their origins to sell their properties and collect money, till they come to Addis the disease develops to its advanced stage. Secondly, she stated that cervical cancer affects patients physically, socially and psychologically. Hence she recommended that for black lion hospital to have counseling department which can provide psychosocial support for cancer patients in general. She also added that most of cervical cancer patients are very poor that they stayed without any diagnosis and medication for two or three years. When they come to black lion hospital it becomes difficult to treat their advanced illness. Furthermore, she explained:

Culture also affects the advancement of cervical cancer. For example early marriage should be abolished in order to prevent young women from the development of cervical cancer. In Ethiopian context no single lady would tell her family that she is having a constant bleeding or vaginal discharge. Even those older patients from Addis would tell anything, in case if their children noticed the bleedings that they would take them to the hospital. In addition depending on the stage of cervical cancer, sometimes the uterus might be removed through surgery; in turn after this procedure is done the patient wouldn't conceive a baby. Therefore, women especially face some physical and

psychological problems through the time. In addition while taking radiotherapy treatment women patients may experience vaginal contraction which in turn may bring urination problem and sexual libido.

Similarly Nurse stated that nutrition and family support is very crucial for cervical cancer patients. She stated that most patients from rural areas come to the hospitals by themselves since they are stigmatized and experienced intimacy issues and financial crisis. Furthermore she reported that since the side effects of the treatments are painful, the patients could not play their mother and wifeness roles in the family. The patients are not capable of taking parts in social affairs such as in weddings and funerals, as they are coming every fifteen days in addition to their appointments for investigation and admission.

Chapter Five

Discussion of Major Findings

From the findings, it is evident that diagnosis with cervical cancer was complex experience for the participants. According to Andrykowski, Carpenter, and Munn, (2003), immediate reactions to the diagnosis of cancer may include disbelief, denial, anger, depression, anxiety, and confusion. In this study all of the participants also reported that they experienced feeling of confusion, anxiety, fear, stress, hopelessness and strain after recognition of their diagnosis with cervical cancer. Apart from the above it was also noted that existing factors like family and friends, religion or spirituality played important roles in assisting patients to cope up with cervical diagnosis result.

As the findings of this study indicate, most of the participants were from rural areas of the country and with the low socio economic backgrounds. More over the participants didn't have any information about cervical cancer before their diagnosis. Due to this lack of awareness some stayed just using traditional treatments and holy water by considering it as evilly attack and as simple temporary pain without going the medical hospitals for a long time. On the other hand some patients responded that though, they went to different hospitals in their perspective localities, they couldn't get a solution for their pain at early stages, except some pills and wrongly diagnosing of the disease with names unrelated to cancer. This finding is consistent with Adnew, Davila, Blumenthal, Shiferaw, Ansel, and Sisay, (2009), who demonstrated that though cervical cancer is preventable and, in most cases curable, if identified in its early stage. But Ethiopian women, by the time they seek screening services the cancer is often at an advanced stage (P.5)." Addis Tesfa(2010,P.9) and Addis Mulugeta (2009,P.78) also added As a

major public health problem, the disease disproportionately affects the country's most vulnerable, poor and rural women.

According to the findings of this study, patients have inadequate information and awareness towards cervical cancer and its treatments. Almost all participants linked their illness with some sort of evil attack, curse, misfortune and punishment from God. Though patients acknowledged the use of the treatments for their health improvement, by hook or by crook they more valued religious rituals and divine interventions as a solution for their health problems. On the other hand some patients without perceptive understanding of the stages of cervical cancer, they considered it, as it is hundred percent curable. Consequently all this misperceptions and misunderstandings of cervical cancer patients created another obstruction for the health service delivery and for their long term quality of health after their medication.

After being diagnosed with cancer, patients report in coping with work, caring for their family as well as severe pain that interferes with their general social life (Baileff, 2000, P. 23). Based on the findings of this research, most of the participants similarly reported that their role performance both at work place and in home changed immediately after their diagnosis. Some reported that they had resigned from their jobs; others couldn't promote to higher positions. On the other hand some quitted from school while those patients who got children's could not raise their children properly.

On top of the above, based on the finding of this study, women patients couldn't play their maternal and wife hood roles in their house following to their diagnosis with cervical cancer. Moreover some of the patients while coming to Addis Ababa for their treatments every fifteen days in addition to waiting their long appointments for investigation and admission could

not take part in social affairs such as in wedding and funerals. Their roles are lost and discontinued due to the impact of the illness and the treatments in general. This finding is in conformity with Misham and Hubel (2001, P. 14), who stated that “cervical cancer survivors experience persistent medical, psychological, social, and relational concerns.”

Blanchard, Albrecht, Ruckdeschel, Grant, and Hemmick,(1995, P.220) argued that social support plays a major role in reducing or buffering negative psychological responses such as hopelessness, despair, and depression in cancer patients. Having someone to whom patients can confide their fears and concerns, a loving and supportive spouse or friend, appears to enhance their emotional state while facilitating the ability to cope more effectively with their illness. According to the findings of this study, interpersonal relations of patients with the family, coworkers, friends, and religious groups and significant others were affected after the diagnosis with cervical cancer. Some couldn't visit their relatives or friends like the previous days, while some patients are forced to be separated from their children while staying and having their medication in Addis Ababa. On the other hand others revealed that they couldn't have someone who can look after their children while regularly traveling to their treatment from their locality to Addis Ababa. Thus one can conclude that their social support set-ups were also narrowed following to the diagnosis. However some participants reported that with the help and the social supports of their significant others that they cope-up with the situation.

In conformity with the findings of this study, after recognizing the diagnosis with cervical cancer, some patients dealt with their illness by directly considering the use of treatment as a major solution for their health problems. Despite the fact that some patients explained that in addition to the treatments they have managed their sickness by enchanting different measurements and activities like through the discharge of their emotions for the diagnosis result

such as by crying, by taking advices and guidance from religious leaders and health professionals. Moreover patients cope-up with their illness through prolonged social support from the families and friends in addition to the use of holy water, prayer and other religious rituals.

In this study, research participants revealed that they have experienced the signs and symptoms of cervical cancer such as excessive bleeding, vaginal discharge, urine and defecation problem, back pain, mouth soreness and physical weakness. Furthermore in the course of treatment, chemo treatment users reported that they have faced health troubles like diarrhea, fatigue, vomiting, low appetite, and loss of hair and stomach disorder. On the other hand radiotherapy users demonstrated that feeling of dizziness, constipation, nausea, diarrhea, skin rash and discoloration were the side effects of radio therapy treatments. Key informant and some patients also reported after radiation treatments due to vaginal contraction patients experienced difficulty in their sexual life and during urination. This finding is consistent with Kornblith (1998) who stated “radiation therapy have side effects such as skin reaction in the area of treatment, fatigue, upset stomach and loose bowels, problems with urination, may lead to pain during sexual intercourse (P.29).” Despite the fact the treatment side effects were difficult to manage; cervical cancer patients demonstrated that their health improvement overshadowed the disruptions of the treatments.

Based on the findings of this study, patient’s contribution in social affairs were very deprived following to their diagnosis with cervical cancer. However their Religious affiliations helped them to relieve symptoms of anxiety and depression by offering a social network. Almost all participants pointed out that their participation in religious activities augmented bearing in

mind that they would discover righteous intervention for their illness. Some participants reported that they went to the Orthodox Church regularly to find holy water and forget their health misery. Muslim religion follower also told that she went most often to the mosques to pray or have ‘*Dua*’ and since it was only three month that she has started her medication, she was able to participate in other social affairs such as *Iddir* and *Iqube* too. On the other hand some reported that they have strong fellowship with their prospective church members in addition to their partaking in a prayer lines and other church service.

However, one participant reported that she was completely distance away from the church and prayer services after her diagnosis due to losing hope in her spiritual life however she was insisted to turn by her Christian friends from the church hence she was able to normalize her life as before. This finding is similar with Gil and Gilbar (2001), who demonstrated that “Patients who perceive cancer as a death threat and view their life as meaningless have more symptoms of depression, with hopelessness as an outcome of those feelings (P.105).” However Patients who have strong social support have less symptoms of hopelessness

According to The Ethiopian Herald (2013, September 22), “there is no cervical cancer-screening program in place in Ethiopia” In this study most of the participants who are from rural part of the country, also reported that there is no a quality of screening services for cervical cancer in their prospective localities. Though, patients had gone to different hospitals in their origin before they made their diagnosis in Black Lion Hospital, they never heard any health issues related to cancer there. Due to this lack of screening service most of the cervical cancer patients were forced to come to black lion hospital in its overdue stage. According to the key informant, to the researcher surprise, there is only one governmental institution in Addis Ababa which gives cervical cancer screening test.

As the findings of this study indicate, cervical cancer patients are facing different confrontations in relation to the health care service provision in Black Lion Hospital during the diagnosis and in the course of their treatments. Patients reported that despite the fact there is shortage of bed for admission and number appointments per one cycle of treatments are very long, Patients are deteriorated from the continuation of pervasive transparency problem of liaison office which is responsible to offer beds for patients. Based on the findings, those poor patients who don't have money to stay in hotels or food to eat in addition to their illness sufferings are forced to sleep barely in the hospital compound, while very few existing beds are unfairly given to the relatives of the staffs with overtone 'social.'

Beyond the expensiveness of cervical cancer treatments, the accessibility to buy it from the hospital is also hard. Furthermore patients are obligated to make laboratory tests and other investigations in privet hospitals due to the shortage of medical equipments in Black Lion Hospital. The distant of the treatment services from periphery areas and Amharic language difficulty among the patients and work load among health professional created poor communication and misunderstandings about the illness and the treatments to the patients. In addition to lack of resources in the hospital, patients and health workers are in proportional, there is no also palliative care center in the hospital this in turn affected the quality of service provision to cervical cancer patients. Similar explanations are also found from multiethnic studies conducted in USA, stated that women with a cervical cancer diagnosis are disproportionately challenged by lack of resources including quality, affordable health care and psychosocial services (Kimlin , Ashing, and Marjorie, 2010, P.10).

In this research patients also explained that they experienced financial crisis subsequent to their diagnosis with cervical cancer. Patients were forced to sell their belongings; oxen,

sheep's, their parent's crop and land moreover borrowed money from bank and churches to have their medication. Some patients since they resigned from their preceding jobs due to their illness, they couldn't even be able to cover their transportation cost while they come to the hospital.

Some of the patients from rural areas came to the hospital all alone by themselves, since they couldn't cover transportation cost, food, shelter and other supplementary stuff for two people while waiting for admission and doing other investigatory tests in the hospital. On other hand some of the patients who are farmer by their occupation couldn't harvest their crops in while traveling from their local areas to the treatment locations. Though some of the patients' treatment costs were fully covered by their family members and friends, they were disappointed for being dependent on others and for not repaying back. A research conducted by Vess (1999), also confirmed that:

During the treatment phase, a major concern for some patients is their physical decline and the threat to psychological and financial well-being. Because many patients are unable to work during their treatment, they miss the sense of self-esteem and pride they used to get from their work. The very real concern, faced by many, of financial insecurity and significant loss of family income forces some debilitated cancer patients back to work before they are able (P.93).

According to IOM and NRC (2006) report, Cancer Patients experience more generalized worry; fear for the future; inability to make plans; uncertainty and a heightened sense of vulnerability; and other worries, changes in one's role within the family and other relationships (P.38). On this study, patients were encouraged to speak about their future plans In relation to connecting themselves with the family, community and follow up of their treatments.

Most of the participants except three hopefully stated if they got well that they have plans to raise, educate and wed their children and see their grand children in the coming decades. More over they made sure that they would follow their treatments, have a good relations with their significant others and their respective religious associations. Some of the patients also stated that they would repay their families favors. On the other hand some were reluctant about their future.

Chapter Six

Conclusion and Implications of the Study

Conclusion

The objective of this study was to explore the psychosocial experience and needs of cervical cancer patients. This study, to attain its objectives, has generated rich amount of information through in-depth interview with cervical patients and health professionals working in the study site. The study has based its inquiry mainly on the psychosocial experiences and needs of the participants. Existing literatures on issues relevant to the subject of inquiry have been reviewed to ground the study and demonstrate basic findings. Even though cervical cancer is affecting large number of women in Ethiopia abundant studies that devoted to the inquiry of cancer related issues in general haven't been found, specific studies on the psychosocial experiences and needs of cervical cancer patients in the context of Ethiopia is barely done. Hence in this study it has been tried to explore their experiences during the diagnosis and in the course of their treatments. It has been tried to gather as in depth information as possible on the experiences of patients through interviews. The finding of this study cannot be generalized for all Ethiopian cervical cancer patients but it could serve as a baseline for other studies.

Findings from this study indicated that women who were diagnosed with cervical cancer have faced with tremendous physiological, psychological and social challenges as a result of their illness. The challenges they have faced following to their diagnosis and in the course of their treatments were not only tremendously personal but affected various levels of their personal, family, professional and social lives.

As the findings of this study indicates, lack of screening service in the origin, distant of the treatment location, inaccessibility of beds for treatment admission, non affordability of

treatments, poor communication among the health professional and the patients, lack of information about the illness and its treatments, intimacy issues and separation from families and loved ones, remission of the illness after some stage of the treatments, financial crisis, depression and hopelessness were found to be patients' psychosocial need during their diagnosis with cervical cancer and in the course of their treatments.

However, religious involvements provided cervical patients with an important construction to explore the meaning and purpose of their lives develop or maintain support systems. For patients religion provided a means of coping with the challenges that accompany with their chronic pain, isolation and dependence following to their diagnosis. Religious coping methods such as prayer, use of holy water, ritual, conversation with priests and pastors have helped patients to have psychological, physical, spiritual, and emotional strength. Furthermore, families and friends support also helped the patients to cop up with their diagnosis results along with the treatments' side effects in general.

Implications

Implication for social work intervention: The findings of this study imply that social workers can intervene in many aspects of cervical cancer patients lives. As the findings of this study indicate diagnosis with cervical cancer and its treatments are very stressful and can bring up many topics and issues for both the patient and their loved ones. Therefore, by engaging bio psychosocial model and family system theory, Social workers can intervene in the provision of quality and sustainable counseling service to cervical cancer patients and their families. Social worker can be also an advocate for expansion of such services particularly in health care settings. Social workers need to bring their knowledge, skills, and compassion to actively listen in unique and dedicated ways, bear witness to patient's physical and emotional pain without abandoning

them; and provide a non-judgmental setting for patients to share and struggle with their joys, regrets, fears, strengths, and weaknesses. Social workers need to help patients with practical needs, like finding resources in the hospital setting and the community, and with such complex needs such as adjusting to an illness, dealing with transitions and decision-making, navigating cultural issues, and communicating with family members, friends, and health care providers. Social workers are also the major activists in promoting the awareness of the public towards cancer and its prevention. Furthermore, social workers can also participate in policy formulations. Through social workers participation in policy formulation, they can take the necessary knowledge and expertise with them that help to consider the needs and rights of cancer patients in policies.

Implication for Social Work Education: Health Social workers need to be educated and develop the skills to assist with the psychological, social, emotional, and spiritual issues that patients have to deal with in cancer (oncology). In order to work with the cervical cancer patients the first thing social workers need to have is adequate knowledge on cancer and the psychosocial experiences and needs of the patients themselves. Such topics should be incorporated in social work health stream courses. In addition, psychosocial counseling courses should also attempt to give basic skills of working with oncology (cancer) related issues. Social workers need also be more involved in research, designing, conducting, and leading studies that aim to advance knowledge that ultimately will help improve patient's quality of life and work as part of oncology care teams.

Policy implications: According to the findings of this study access and quality problems exist in the health sector. The government should give priority in developing of healthy milieu and increasing access to health services to cancer patients, especially in regional level, in turn

prevents patient crowding and delayed care at Black Lion Referral Hospital. Together with, improvement of the accessibility and the availability of cervical cancer screening services and chemo radiation centers with all technological equipments and with well trained health professionals in regional level government need to intervene at this point in time. In this study, it is also found that patients do not have adequate information about cervical cancer causes, prevention and its treatments in general, therefore the effectiveness of the existing information, education and communication programs should be taken into account. Though, Prevention of cancer requires multi sectoral and serious efforts, government needs to take the first and highest responsibility to enhance greater awareness about cancer to the public both at federal and at regional levels. Ethiopian health policy gives more emphasizes to communicable diseases but non-communicable and chronic diseases are not mentioned anywhere in the policy document. Therefore Policy makers should advocate the review and modification of the existing Ethiopian health policy in practical manners. Moreover, policy makers should ensure adequate resource allocation for the establishment of health facilities like cancer screening services and chemo radiation treatments centers in remote areas of the country.

Implication for Health Practitioners and the Institution: The study has indicated that there are problems in allocating resources like beds and treatments for patients fairly. Hence there should be equal opportunity in the hospital to utilize services available to all patients regardless of their region, social class or familiarity to the organizational members. There are also unbalanced proportionality between the patients and health workers in the oncology center. Therefore more oncologists need to be trained to fill the gap. Furthermore, the few existing hospital care teams need to strive more to help cervical cancer patients to navigate their way

through treatment, consider options, cope with their feelings, and help them cope with everyday practical challenges in a way that focuses on what is best for patients and those close to them.

Hospice and palliative care centers should be assembled in the hospital setting to address physical or emotional pain and suffering of cancer patients in general and cervical cancer patients in particular. The researcher would also like to postulate multidisciplinary support programs, incorporating adequate information regarding the specific cancer such as cervical cancer and its treatments (psycho-education), preparation for all treatment modalities and the addressing of social adjustments and psychological adjustments such as stress, trauma and hopelessness related to their diagnosis are crucial to the holistic cares of patients diagnosed with cervical cancer. Such a program should be available to the patients and their families from the diagnosis onwards and should integrate psychosocial needs such as, diagnosis, expense, treatments, remission, survival and terminal phases need to be addressed in such a program. Moreover, the implementation of psychosocial intervention programs in which the patients and patient's family can receive ongoing counseling during diagnosis and in all treatments phases in the hospital is advisable in this regard.

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Appendix A

Informed Consent Form

Greetings! My name is Konjit Kebede. I am from School of Social Work at Addis Ababa University. I am currently collecting data for my Thesis project entitled “The Psychosocial Experiences and the Needs of Cervical Cancer Patients in Black Lion Referral Hospital” the aim of the intended research is to capture and explore the psychological and social experiences patients towards cervical cancer diagnosis and treatment. It is also aimed at identifying the patients need so that appropriate interventions would be designed for the issues from the responsible organs. For the successful completion of the study, the cooperation of those who are diagnosed with cervical cancer and capable of providing necessary data is essential.

The participants of the study will be women patients over the age of eighteen years, diagnosed with cervical cancer, and who have started treatment of the cervical cancer in Black Lion General Referral Hospital, have the ability to make conversations in Amharic language and have the ability to contribute to the understanding of their psychosocial experiences and needs regarding the issue.

I will conduct one-on-one interview. During this process, I would like to assure you that your identity will not be disclosed to anyone. This is to protect your privacy and confidentiality of the information you will provide. I will use tape recorders to correctly record the conversations we will make, and the recordings will be locked in a safe place and will not be exposed to anyone. This, will, however to be done based on your willingness and permission. The notes and tapes will be destroyed after the study is completed and approved by the School of Social Work. You have the right to decline from responding to some questions or quitting

participation in general. However, your honest answer to the questions and inclusive participation will help me to better understand and interpret the psychosocial experience and needs you have with regard to cervical cancer diagnosis and treatment.

By signing this form, you agree to participate in this research under the conditions described above.

If you have any question any time after the interview, you can contact me by the following telephone number: 0911070222

Email: konjit_k@yahoo.com

Name of participant (pseudonym) _____

Date _____

Signature _____

Name of the interviewer: Konjit Kebede

Date _____

Signature _____

Appendix C

Interview Question Checklists for the Study on: Psychosocial Experiences and Needs of Cervical Cancer Patients

I. Socio-Demographic Characteristics of Respondents

Age _____

Religion _____

Ethnicity _____

Marital status _____

Educational level _____

Place of residence: Rural _____ urban _____

II. Psychosocial Experiences and Needs

1. How did you experience the reports of your diagnosis with cervical cancer?

Probing question: did you have any information about it before your diagnosis?

2. What were your emotional reactions and responses towards cervical cancer diagnosis?

Probing questions: have you experienced depression & stress or Feelings of hopelessness and helplessness as a result of cervical cancer diagnosis?

3. How your diagnosis did influence your family and social life?

Probing questions to be considered under this inquiry

- a. How do you describe your role performance both in work place and at home after the diagnosis?

Probing questions: did cervical cancer affect the amount of work you do; have you felt upset, worried, or uncomfortable while doing your work after your diagnosis?

- b. How do you explain your interpersonal relations with friends and relatives?

Probing question: Are there any issues/concerns about your intimacy after your diagnosis?

- c. Have you been under or felt you were under any strain, stress, pressure or stigma because of your diagnosis?

- d. Are you bothered by any difficulties in your sex life? How well are you fulfilling your sexual needs?

III. Treatment related Issues

4. What kinds of treatments have you obtained from the hospital after the diagnosis?

Probing questions: was the treatment surgery, chemotherapy, radiotherapy or any other?

5. How did you experience your treatment?

Probing questions: Do you have any particular physical or health trouble after you have started treatment?

6. How did you interpreted and responded to cervical cancer treatment?

Probing questions: how do you describe your emotional reactions, responses and the influence of existential factors for the treatment?

7. What is the effect of the treatment on your long term quality of life?

Probing question: does your health improvement after treatment outweighs the disruptions or vise versa?

IV. Post Treatment Quality of Life

8. How do you manage your life after having recognized your diagnosis with cervical cancer?

Probing questions:

- a. Whom do you consult in case of treatment problems?
 - b. How often do you participate in religious activities such as prayer, use holly water or attend a religious service after your diagnosis?
 - c. About how many voluntary groups or organizations do you belong to—like church groups or associations like Idir etc. (“Voluntary” means because you want to.)
 - d. How active are you in the affairs of these groups or associations s you belong to?
(If you belong to a great many, just count those you feel closest to. If you don’t belong to any, we can jump this question)
9. Would you tell me what your psychosocial needs were after the diagnosis and in the course of the treatment?

Probing questions:

- a. Would you like to tell me if there were any screening services for cervical cancer in its early stage in your area of location?
- b. How convenient is the treatment unit location /services for you?
- c. Have you had enough money to take care of your own and your family’s financial needs after the diagnosis?
- d. How satisfied are you with the support you get from your family?
- e. What is/are your future plan in relation to:
 - a. Continuing your participation in family and community life

- b. Follow-up of your treatment
- c. Connecting yourself with the existing support groups (if there is any at all).

Appendix D

Interview Guiding Questions for Patients in Amharic Version

ከሚገኝ ካንሰር ምርመራና ህክምና ጋር ተያያዘው የሚጠቀሙበት ሥነ ልቦናዊ ሁኔታ መጠይቆች

I. የሰነ ህዝብ ጥያቄዎች

እድሜ _____

ብሄር _____

የትምህርት ደረጃ _____

የትዳር ሁኔታ _____

ሐይማኖት _____

የመኖሪያ አድራሻ ከተማ _____ ገበያ _____

II. ማህበራዊና ሥነ ልቦናዊ ተግባራዊ መጠይቆች

1. የምርመራ ወጠኛውን በሰማኝበት ወቅት የነበረሽ ሁኔታ ምን ይመስላል?

ሚጋገጥህ፡ ከምርመራ ወጠኛው በፊት ስለ ማህጸን ካንሰር የነበረሽ ሚጋገጥ ምን ይመስላል?

2. ስለሚገኝ ካንሰር ምርመራ የነበረሽ ሥሜት አጸፋና መልስ ምን ነበረ?

ሚጋገጥህ፡ የምርመራ ወጠኛውን ተከትሎ የመጣ እንደ ደባቴ፣ ተስፋ መቅረጥ የመሳሰሉ ስሜቶች

አጋጥሟል?

3. የሚገኝ ካንሰር ህመም በቤተሰቦችሽና በማህበራዊ ህይወትሽ ላይ ያመጣውን ጭንቀት ብትነግራኝ

የሚጋገጥህ ጭንቀቶች

ሀ. የሥራ ላይ ካንሰር ህመም እንዳለብኝ በህክምና ካረጋገጥኝ በኋላ ቤት ውስጥ በስራ ቦታ ያለኝ ሁኔታ ምን ይመስላል? ህመሙ የምትሰራውን ሰራ በምን አይነት ሁኔታ ተጽእኖ አሳድሯል? በምትሰራበት ወቅት ሀዘን፣ ጭቀት የመሳሰሉ ሥሜዎች ይሰማኛል?

ለ. ከጋደኞቻችሁ እና ከዘመዶቻችሁ ጋር ያለኝን ግንኙነት ምን ይመስላል?

የሚረጋገጡት ጭጥያቄ ከህክምና ወጠኛቸው በሃላ የወዳጅነትና የቅርብነት ችግር አጋጥሞኝ ያወቃል?

ሐ. ባንቺና በቤተሰቦቻችሁ ላይ ከካንሰር ህመም ጋር ተያይዞ የመጣ ወጥረት፣ ድካም፣ ጭቀት ወይም መግለል ካለ ብታጠቃላይኝ?

መ. በግብረሥጋ ግንኙነት ወቅት ከህመም ጋር እና ከህክምና ውጥረት ያጋጠሞኝ ችግር ካለ በትኩረት ግራኝኝ፣ ምን ያህል ያንቺና የባለቤትሽ የወሲብ ፍላጎት ተሟልቶአል ብለኝ ታስቧል?

III. ከህክምና ውጋር ተያይዞ ያለ ሁኔታዎች

4. የሥራ ላይ ካንሰር ህመም እንዳለብኝ ካወቅኝ በኋላ ከጥቁር አንበሳ ሆስፒታል ያገኘኝው የህክምና እርዳታ እና አገልግሎት ምን ይመስላል?

የሚረጋገጡት ጭጥያቄ : - ያገኘኝው የህክምና አገልግሎት ከምትገባው፣ የጨረራ ህክምና ወይስ ቀደጥንና

5. የህክምና ክትትሉንና መድሃኒቱን እንዴት አገኘኝ?

የሚረጋገጡት ጭጥያቄ : - ህክምናውን ወይም መድሃኒቱን ከጀመርኝ በሃላ ከነበረብኝ ህመም በተጋዳኝ ያጋጠሞኝ ሌላ የጠፍ እክል (ችግር) ካለ ብትኩረት ግራኝኝ?

6. የጎረቤት ችግሮቼና ህክምናውን እንዴት እንዳቻቸልኝ ብትኩረት ግራኝኝ?

የሚረጋገጡት ጭጥያቄ : - ባጠቃላይ ሥሜታዊ አጻፋዎቻችሁና መለሰችሁ እንዲሁ ያለው የኑሮኝ ነባራዊ ሁኔታ በህክምና ክትትሉና በጠፍነት ላይ ያመጣውን ተጽዕኖ ብትኩረት ግራኝኝ?

7. የህክምና ውእርዳታና መድሃኒቱ በጠፍነት ላይ በህይወትሽ ላይ ያመጣውን አዎንታዊ ወይም ሚናዊ ተጽእኖ ምን ምን እንደሆነ ብትኩረት ግራኝኝ?

የሚጋገግ ጫጥያቄ ፡ - የምትጠቀሙቸው መደሃኒቶች የጎኔዮሽ ችግሮቹ ወይስ ጥቅሙ ያመዘናል ብለሽ ታስቢያለሽ?

IV. ድህረ ህክምናና የህይወት ሁኔታ(ለጠጥ)

8. የሚጠቀሙ ካንሰር እና ዳለብሰሽ በህክምና ካረጋገጥሽ በሃላ የወሰድሽዉ የ ጭትሄ እርምጃዎች ምን ምን ነ በር እንዴት ሜጅ አደረግሽዉ

የሚጋገግ ጫጥያቄዎች

ሀ. በህክምና ዙሪያ ችግር ሲያጋጥሙሽ ለምሳሌ መደሃኒቱ ሳይሰራ ሲቀር የምታሞክራዉሰዉ ማንነ ወ;

ለ. ከህክምና ባለሙያዎች ጋር ያለሽ ግንኙነት ምን ይመስላል

ሐ. የሚጠቀሙ ካንሰር እና ዳለብሰሽ በህክምና ካረጋገጥሽ በሃላ ምን ያህል ጊዜ በሀይማኖታዊ ክንወኛች እንደ

ፀሎት ፣ ፀበል ማጠቃለያ፣ ወዘተ ወይም በ/ክ ወስጥ ወይም በመስጊድ በሚደረጉ የሃይማኖት ተግባራት ላይ

ትሳተፈያለሽ

መ. ህክምናዉን ከጀመርሽ በሃላ የራስሽንና የቤተሰቦችሽን ፍላጎት ማሟላት በቂ ገንዘብ አለሽ

ሠ. ለህክምናዉ የምታወጧዉ ገንዘብ በወር ምን ያህል ይሆናል;

ረ. ከቤተሰብ በምታገኝ ሂደታዎችና እርዳታ ምን ያህል ደስተኛ ነሽ

9. የ ወደፊቱ እቅድሽ ምን ድኅ ወ;

የሚጋገግ ጫጥያቄዎች

ሀ. በቤተሰብና በሚበረሰቡ ዙሪያ በሚደረጉ እንቅስቃሴዎች ተሳታፊ ለመሆን ለወደፊት ያለሽ እቅድ ምን ድኅ ወ.

ለ. የህክምና ክትትሉ ጋር በተያያዘስ

ሐ. ራስሽን ካሉት ድጋፍ ሰጪ ሚዛን ስራትና አካላት ጋር ከመግባት ነገት አንጻር

Appendix E**Interview checklists for health professionals working with cervical cancer patients**

Age _____

Sex _____

Educational level _____

Profession _____

1. From urban or rural areas, do most of cervical patients come to black lion hospital?
2. Does cervical cancer more affect women from lower socio economic class or all women society?
3. How do cervical cancer patients react during their diagnosis result is told and to the treatments in general?
3. After use of some cycle of radiation and chemo how do patients react and respond to the treatment?
4. How much do you think cervical cancer patients had appropriate information about cancer before their diagnosis?
5. How much is black lion hospital taking part to create awareness to the public about cancer in Ethiopian context
6. How much do you think the services rendered in black lion hospital are effective and efficient enough?
7. Do you think number of patients and health professionals working in black lion hospital are proportional?
8. From my direct observation most of patients complain about the number of appointments for one cycle of radiation and chemo services and they are also disappointed with the insufficiency of beds for admission. What has been done by Black lion Hospital staffs and by government so far to solve this problem?
9. How much do you think the information provided by the health professionals about cancer and its treatments are effective?

10. Most of patients who are taking chemo think cancer is curable through its treatments. From where do you think this perception and attitude come? Is the source of info from the health professionals or the patients themselves?
11. Is there any consultancy services available for cancer patients in black lion hospital?
12. Is there any palliative care services available in black lion hospital? If yes how much is that effective in relation to involving professional from other field of expertise such as health social workers, psychiatrist and other?
13. How much do you think free service user patients and those who pay for service charges are equally treated in relation to bed for admission and other medications?
14. Do you think the availability and the accessibility of chemo and other services are efficient in country wide?
15. What do you think the psychosocial needs of cervical cancer patients during the diagnosis and in the course of the treatments?
16. Does cervical cancer have any effects on women patient's schemata and their body structure?
17. What do you think the changes and the transformation that would brought if other chemo radiation centers in regional level is established?
17. What do you think the roles of government, health professionals, the society and other responsible organs in relation to cancer prevention, treatments and in creating awareness would be?



አዲስ አበባ ዩኒቨርሲቲ የሕክምና ፊኩልቲ
የሚዛገንና ፅንሰ ትምህርት ክፍል

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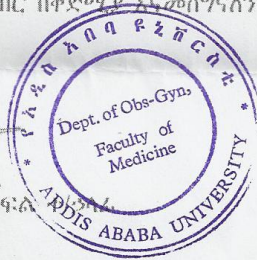
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ቁጥር: ለት/ሚዛ/8971/2006

ለሚመለከተው ሁሉ

በአዲስ አበባ ዩኒቨርሲቲ ሶሻል ወርክ ት/ቤት ውስጥ የድህረ ምረቃ ተማሪ የሆኑ
ወ/ ቆንጆት ከበደ “The Psychosocial Experiences and the Needs of Women
Patients Diagnosed with Cervical Cancer: The Case of Black Lion Hospital
Cervical Cancer Patients” በሚል ርዕስ የመመረቁ ጥናት ጽሁፍ ፕሮፖዛል
በማህፀንና ጽንሰ ት/ክፍል የጥናትና ምርምር ኮሚቴ ታይቶአል። ስለሆነም
ለጽሁፋቸው መረጃዎችን ለመስጠት ይችሉ ዘንድ ትብብር እንዲደረግላቸው እየጠየቅን
ለሚደረግላቸው ትብብር በቅድሚያ እናመሰግናለን።

ከሰላምታ ጋር

ዶ/ር እስክንድር ከበደ
የሚዛገንና ፅንሰ ት/ክፍል



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Declaration

I declare that THE PSYCHOSOCIAL EXPERIENCES AND NEEDS OF WOMEN PATIENTS DIAGNOSED WITH CERVICAL CANCER is my own original work and has not been presented for any degree in any other university, and that all sources of materials used for the thesis have been dully acknowledged.

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