Psychosocial Impact of Childhood Cancer on Parents with Children Diagnosed with Cancer: The Case of Parents Receiving Service at Tikur Anbessa Specialized Hospital

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This is to certify that the thesis prepared by Atsednesh Getachew, entitled *Psychosocial Impact of Childhood Cancer on Parents with Children diagnosed with Cancer: The Case of Parent Receiving Service at Tikur Anbessa Specialized Hospital* and submitted in partial fulfillment of the requirements for the Degree of Master of Arts (Social Work) complies with the regulation of the University and meets the accepted standards with respect to originality and quality.

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Declaration

I declare that *Psychosocial Impact of Childhood Cancer on Parents with Children diagnosed with Cancer: The Case of Parents Receiving Service at Tikur Anbessa Specialized Hospital* is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of reference and that the work has not been submitted before any others degree at any other institution.

Atsednesh Getachew Mengesha

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Date: July 4, 2014

Place: Addis Ababa University, Ethiopia

ABSTRACT

Cancer, one of the non-communicable diseases is gaining momentum in Ethiopia. As the country has only one cancer treatment center for both adults and children, the challenges associated with that are immense. In line with that, this study, focused on identifying the psychosocial impacts parents of children diagnosed with cancer have and how they cope with those impacts. Qualitative approach particularly case study design was used in this study. The tools for primary data collection were in-depth interviews and focus group discussions in order to gain in-depth information. Purposive sampling technique was used to select participants leading to sixteen parents of children with cancer who are currently following either admitted or as an outpatient to be involved in the study. In addition to that, three health care professionals were involved as key informants. The findings of the study reveal that parents with children diagnosed with cancer had encountered different psychological, social and physical impacts that are interdependent on one another. In addition to that, parents use different problem and emotional focused coping strategies to mitigate the challenges they encounter. Different informal and formal support systems also assist them to cope. However, the findings also show that the support parents are receiving is more inclined towards social support neglecting the psychological problems they have. The findings of the study present social work implication in the areas of practice, education, research and policy.

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Acronyms and Abbreviations

CT – Computerized Tomography

FMOH – Federal Ministry of Health

HSDP- Health Sector Development Plan

INCTR-USA - International Network for Cancer Treatment and Research, USA

NCD – Non-Communicable Diseases

PCS – Physical Component Score

PTSS – Post Traumatic Stress Symptomtology

TAPCCO - Tesfa Addis Parents Childhood Cancer Organization

TASH – Tikur Anbessa Specialized Hospital

WHO - World Health Organization

CHAPTER ONE: INTRODUCTION

1.1. Background

Cancer, known for more than 3000 years, was branded as the disease of the developed world with 70% prevalence in the 19th century (Aynalem Abreha, 2013, pp. 1-11). However, currently the disease is affecting "under developed" countries such as Ethiopia and is being a health burden. For years, Ethiopia's health policy focus was prevention, care and support of communicable diseases such as HIV/AIDS, tuberculosis, malaria, childhood diseases that cause high mortality rates in less than five years of age, which is understandable due to the magnitude of effect and rate of transmission communicable diseases, and did not put due consideration to the effects and disease burden arising from non-communicable diseases such as cancer. Nevertheless, the current health sector development plan (HSDP IV) has recognized the impact of non-communicable diseases is creating and had incorporated prevention and treatment aspects (Mename Feleke, 2013, p. 1).

Ethiopia's health care system focuses on prevention and treatment of disease, whether communicable or non-communicable, for patents from all walks of life (International Network for cancer treatment and research, 2010 as cited in (Mename Feleke, 2013, pp. 1-2). The bio-medical model that governs the health care in Ethiopia lacks to consider the interdependence between mind and body with social aspects of individuals. Similarly, health problem developed on an individual also creates tremendous impact on that family system and more broadly on the community.

The focus of this study is on identifying and describing the different psychosocial impacts parents of children with cancer face and how they try to cope with those challenges. The topic of interest is chosen for the reasons that the burden of non-communicable diseases in general and cancer in particular is rising which signifies that associated impacts are also rising on those diagnosed with the disease as well as their families and for the fact that there is lack of studies conducted in the area of psychosocial aspects of childhood cancer in relation to parents in Ethiopia.

The study area identified in this research is Pediatrics Hematology/Oncology unit of Tikur Anbessa Specialized Hospital as it is the only cancer referral center the country has providing comprehensive care and treatment for adults and children with cancer. Having only one cancer care centre for 80 million populations presents its own challenge for patients and in this case for parents as some will have to travel from different parts of the country leaving behind their children and home in addition to being challenged with the different psychological and social problems. Nevertheless, parents cope with the difficult and unexpected situation they find themselves in and different supports provided from stakeholders assists them to cope better. And this study tries to identify how parents cope with the situation of their child being diagnosed with cancer and what support system enables them to do that.

1.2. Statement of the Problem

Researches by Edwards and Clarke (2004), Kazak (2005), and Pollock, Litzelman, Wisk and Witt (2013) had been conducted to examine the impact of childhood cancer on the children themselves and on families. Edwards and Clarke (2004, p. 567) had conducted a research on the psychological impact of cancer diagnosis on families and had identified that depression and anxiety were accounted by family members with 20.8% and 15% of variance respectively. Furthermore, Kazak (2005, pp. 31-32) had reviewed researches that were conducted in the area of childhood cancer survivors and their families and reported that families exhibit high distress levels during initial diagnosis of their children with cancer. She had also reported that parents' lack of social support poses greater risk for constant challenges.

Pollock, Litzelman, Wisk and Witt (2013, p. 107) on the other hand, compared the physiological and psychological stress among parents with children diagnosed with cancer with those of healthy once and identified that parents of children with cancer exhibited higher levels of physiological symptoms of stress than their counter parts. The research also identified poor quality of sleep and greater negative social interactions were significant among those parents of children with cancer.

Another research conducted by Streisand, Kazak and Tercyak (2003, pp. 252-254) had found out that, families of children on active cancer treatment experience stress when compared with parents with children who had completed treatment that signifies the necessity for psychosocial and behavioral services during the treatment period. The researchers had also reported that stressed parents stated "poorer family behavioral control" and they recommended for a need of support in "establishing and maintaining near normal daily routines during medical crisis". With a specific focus on mothers; Manne, Duham and Redd (2000, p. 380) had conducted a study to see the "association of psychological vulnerability factors to post-traumatic stress symptomatology (PTSS)" in mothers with children who are cancer survivors and had identified that mothers who sensed more restraints in expressing their "thoughts and feelings" to others had experienced traumatic stress symptom. Dolgin, Phipps, Fairclougholle, Sahler, Askins, Noll, Butler, Varni, and Katz (2007, p. 778) had studied mothers' adjustment courses when children are initially diagnosed, at three months and at six months. The result of the research showed mildly elevated negative affectivity and PTSS during initial diagnosis. The result also shows improvement in PTSS, mood disturbance and depression over time.

In relation to types of families who would be to susceptible to psychosocial problems, Karlson, Smith, Haynes, Faith, Pierce, Elkin and Megason (2013, p. 241) had found out that caregivers with lower education achievement and financial difficulties are at considerable risk for psychosocial problems and recommended for early psychological support for parents.

In Ethiopian, there are some researchers conducted in the area of cancer and particularly childhood cancer. In the area of childhood cancer, Yared Tadesse and Etsegenet Gedlu (2008), Telahun Teka (1992) and Bedri Ahmed (1984) had conducted studies with focusing on the biological dimensions of the disease. On the other hand, Dye, Solomon Bogale, Hobden, Yared Tilahun, Hechter, Teshome Deresse, Bize and Reeler (2011), Dye, Solomon Bogale, Hobden, Yared Tilahun, Teshome Deresse and Reeler (2012), Alemayehu Hailu and Damene Hailemariam (2013), Hiwot Wubshet (2010) and Mename Feleke (2013) had conducted studies that focused psychosocial dimensions of adult cancer.

From childhood cancer perspective, Yared Tadesse and Etsegenet Gedlu (2008, Patients and Methods section, para. 1) conducted retrospective analysis study that assessed the pattern of childhood malignancies among children in the age range of three months to twelve years admitted from January 2005 to December 2006 at Tikur Anbessa Hospital. The results of the research indicated that admission due to malignancies accounted for 3.1% of all the admissions at the pediatrics department for that period with Wilm's tumor being the most frequent malignancy. Yared Tadesse and Etsegenet Gedlu (2008, Discussion section, para. 1)

Another study conducted by Bedri Ahmed (1984) identified the different childhood malignancies from 1974-1981 that were observed at the paediatrics clinic of Tikur Anbessa Hospital with lymphomas (28%) being the highest incidence and Burkitt's lymphoma the most common. On the other hand, Telahun Teka (1992) had conducted a retrospective study to determine the pattern of childhood malignant diseases in the paediatrics department of the Gonder College of Medical Sciences for the period 1981 to 1990. The findings of the study illustrated that admission due to malignancy accounts for 0.66% of the total paediatric admissions ages ranging between four months and fourteen.

Dye, et al. (2011) conducted a research assessing "beliefs and practice around breast cancer in Ethiopia". The research had revealed that around 40% of respondents (patients and families) had the sense of fatalism about cancer (Dye, et al. 2011, pp. 722-723). The research had also revealed that there is lack of knowledge among patients to the extent of 35% of the respondents had never heard of cancer prior to their diagnosis. On top of that around 10% patients and families indicated that they had faced "stigmatization and isolation" due to the disease. Another research by Dye et al. (2012, pp. 2-3) that assessed the early symptoms experience of breast cancer and triggers for action had revealed that 69.6% of respondents have stated that they have ignored the first symptoms and 42% of the respondents had seek treatment when they started exhibiting more symptoms.

A research conducted by Alemayehu Hailu and Damene Hailemariam (2011) had tried to establish an approximate costs enumeration that adult cancer patients incur and establish forecasters for variation in cervical cancer treatment in Ethiopia. The study had included 227 cervical cancer patients at Tikur Anbessa Specialized and Teaching Referral Hospital. The findings of the study showed that 'the mean outpatient cost' incurred per patient is $407.20 while that of the inpatient is $334.20 with 74% of the cost related to medical while 26% related to non-medical costs (Alemayehu Hailu and Damene Hailemariam, 2011, pp. 3-4). The researchers had concluded that cervical cancer presents enormous financial burden on patients and families (Alemayehu Hailu and Damene Hailemariam, 2011, p. 7).

The researches of Hiwot Wubshet (2010) and Mename Feleke (2013) focused on the psychosocial care, support and experience of adult cancer patients. Hiwot Wubshet (2010, pp. 38-88) that assessed the psychosocial support experience of blood cancer patients had identified that clients are not receiving adequate and well organized psychosocial support from the hospital (in this case Tikur Anbessa Hospital, the only cancer treating hospital for both for adults and children), their families and other settings for the different psychological, physical, social and economic challenges they have faced. The researcher had also found out that the participants in the study have experienced stress and feelings of hopelessness and helplessness due to the disease. Some participants had also expressed preference of death rather than hearing the diagnosis (Hiwot Wubshet, 2010, p. 91). The study had also reveled that participants had faced psychological disturbances and fear due to side effects of treatments including physical changes, perception of others, loss of reproductive capacities, and others (Hiwot Wubshet, 2010, pp. 89-94).

Another research conducted by Mename Feleke (2013) reported that participants of the study had faced different social and psychological problems due to the disease. The research had found that changes in family and social roles, job loss, financial problems due to diagnostic and treatment procedures, lack of sufficient information about disease and treatment, change of self concept, experiences of stress and anxiety, and effects in sexuality are the different social and psychological impacts of being a cancer patient (Mename Feleke, 2013, pp. 37-53).

I have not found any studies conducted in Ethiopia that had tried to look into the psychosocial issues faced by children diagnosed with cancer as well as by parents of children diagnosed with the disease. This shows that there exists a knowledge gap in the topic of interest initiating curiosity in conducting a research and finding out about the issue. Therefore, this study had tried to identify the psychosocial impact of childhood cancer on parents with children diagnosed with cancer and how parents cope with those challenges.

1.3. Research questions

The general research question this study will answer: what are the psychosocial impacts of childhood cancer on parents and how do parents try cope with the impacts they encounter due to the disease.

The specific research questions of the study are:

What are the psychological impacts of childhood cancer on parents?

What are the social impacts of childhood cancer on parents?

What are the physical impacts of childhood cancer on parents?

How do parents try to cope with the impacts they are faced with?

1.4. Significance of the study

Cancer poses physical, psychological, social and economic impacts to parents when their child is diagnosed with the disease. In line with that, an in-depth study of the psychosocial impact of childhood cancer on parents as well as their coping mechanisms and identifying the types of psychosocial support provided to the parents by health institution, family members and social support systems will be able to serve as a stepping stone in trying to identify the psychosocial challenges parents face as a result of their child's health situation and provide an insight to a situation not so far considered. In addition to that, it will increase awareness of the challenges parents face as a result of their child's diagnosis with cancer. On top of that, it will also assist health and other concerned institutions who are working in the area of childhood cancer directly or indirectly and will also serve as a source for further investigation for other researches in the area.

1.5. Limitations of the study

One of the major limitations of the study is that generalizability of the findings. As the research method used was qualitative study, which focused on attaining adequate and in-depth information on the issue rather than on generalizability. The other limitation of the study is the fact that it did not capture social changes which according to Krueger and Neuman (2006, p.32) is the short coming of cross-sectional research that was utilized in this study.

1.6. Challenges in the study

This study is not without challenges. The first challenge encountered in conducting this study is lack of researches conducted in the area of psychosocial impact or support to people living with cancer in general and in particular to parents or care givers in the context of Ethiopia. Moreover, the study had the intention of conducting two focus group discussion comprising homogeneous groups of mothers and fathers of children diagnosed with cancer. However, it had failed to conduct the discussion with mothers as the number of mother participants acquired was less than the minimum number of participants needed for focus group discussion. The reduction in the number of participants was as a result of some identified mothers were not provided medical counseling and were not informed of their respective children's status while others were newly admitted children for diagnostic purposes. As a result of that, the identified participants were taken off from the study.

1.7. Objective of the research

The general objective of this research is to identify the psychosocial impact of childhood cancer on parents of children diagnosed with the disease the case of parents receiving service at Tikur Anbessa Specialized Hospital and identify how parents cope with those impacts.

The specific objectives of the research, it tries to:

Identify and describe the psychological impacts of childhood cancer on parents,

Identify and describe the social impacts of childhood cancer on parents,

Identify and describe the physical impacts of childhood cancer on parents,

Identify and describe how parents cope with the impacts brought by childhood cancer

1.8. Working definitions of terms

Cancer patient: - a child diagnosed with any type of cancer and who is attending treatment for the disease at Tikur Anbessa Specialized Hospital pediatrics department

Economic impacts: - strain on the financial status of a family leading to challenges in purchasing medications and fulfilling basic needs, work disruptions and at least one parent quitting work

Parents: - biological or legal guardians of a child diagnosed with cancer

Physical impacts: - sleep disturbance or sleeplessness, loss of appetite, weight loss and other health (biological) related problems rising as a result of child diagnosed with cancer

Psychological impacts: - experiencing feelings of anxiety, fear, anger, shock, trauma, stress and depression due to child's diagnosis

Social impacts: - limitations in social activities, marital problems, change of family roles, added responsibilities, and lack of support from family and friends, and economical problems that brings about stress and negative frame of mind

CHAPTER TWO: REVIEW OF LITERATURE

This chapter discusses relevant literatures and research conducted in the area of psychosocial impact, care and support for parents with children diagnosed with cancer. The chapter has four main sections that provide general view on cancer, impacts on nuclear family with main focus on parents, parents coping mechanisms and theories that further explain the impacts and parental coping mechanisms.

2.1. Overview of Cancer

World Health Organization (WHO) reported that non-communicable diseases (NCDs) such as cardiovascular diseases, cancer, chronic respiratory infections and diabetes are the leading threats of death in the world comprising about 60% of all deaths globally and 80% of all death in low and middle income countries causing an estimated 35 million deaths in 2005 (WHO, 2008, p.9). The Ethiopian Federal Ministry of Health (FMOH, 2010, p. 13) had reported that cardiovascular diseases, diabetes mellitus and cancer alongside with injuries to be amongst the major contributors to the high level of mortality and morbidity in Ethiopia. Similarly, WHO had anticipated that 34% of the Ethiopian population would die from non-communicable diseases in the year 2011 (as cited in Awoke Misganaw, Damen Haile Mariam, Ahmed Ali & Tekebash Araya, 2014, p.1).

Cancer is one of the four major non-communicable disease along side with cardiovascular diseases, diabetes and chronic obstructive diseases. Childhood cancer, according to Ferlay, Bray and Mathers (2008) and World Bank, comprise only a small percentage of the global cancer burden with 84% of childhood cancers occurring in low-income and middle-income countries (as cited in Magrath, Steliarova-Foucher, Epelman, Ribeiro, Harif, Li, Kebudi, Macfarlane & Howard, 2013, p. 104). In United States, according to Lanzkowsky (1983), prevalence of malignant tumours, in persons less than 15 years of age, was 12.45 per 100,000 and 9.78 per 100,000 among whites and African Americans respectively (as cited in Yared Tadesse & Etsegenet Gedlu, 2008, Introduction section, para.1). And according to American Cancer Society (2013, What are the key statistics for childhood cancer? section, para. 1), childhood cancer, the second leading cause of death in children, in United States represents about 1% of the total cancer diagnosis each year with an estimated 10,450 new diagnosis in 2014.

In Ethiopia, it is very difficult to find actual figures in regards to non-communicable diseases in general and cancer in particular as there is lack of proper documentation generally and lack of proper cancer registry (Anylaem Abreha, 2013, p. 13; Awoke Misganaw, Damen Haile Mariam, Ahmed Ali & Tekebash Araya, 2014, p. 2; Shad, Challinor & Cohen, 2013, p. 109). However, WHO (2011) estimated that the national prevalence of cancer in Ethiopia to be 4% and Abegunde, Mathers, Adam, Ortegon and Strong (2007) indicated that "Global Burden of Disease (GBD) studies estimated age-standardized death rates of 150 per 100,000 is attributed to cancer" (as cited in Awoke Misganaw, et al. 2014, pp. 1-2). Similarly, Anylaem Abreha (2013, p.13) claim that medical records/information indicate that the prevalence of cancer is increasing with cervical cancer leading with 30%. Similarly Shad, Challinor and Cohen (2013, p. 109) had stated that Tikur Anbessa Radiotherapy Center medical records estimate around 120,500 new cases of per annum. Moreover, a study conducted by Yared Tadesse and Etsegenet Gedlu (2008, Discussion section, para.1) indicated that admission due to childhood malignancies at Tikur Anbessa Hospital from January 2005 to December 2006 was 3.1% of all the admissions.

2.1.1. Causes, Types and Health Consequences of Childhood Cancer

Cancer, a known disease for more than 3000 years (Aynalem Abreha, 2013, p.1), is a neoplastic (a growth of tumor) disorder, that can involve all body organs with manifestations that vary according to the body system affected and type of tumor cells. Cancer occurs when cells lose their normal growth-controlling mechanism leading to uncontrolled cell growth (Silverstri, 2008, p.635). Cancer cells start causing serious health problem when they move from their original location to other site which is referred as metastasis (Silverstri, 2008, p.635). Cancers are classified as solid tumors, when it is allied with the organ from which it develops such as breast and lung cancers, and hematological, when it originates from blood cell forming tissues such as leukemia (Silverstri, 2008, p.636).

There is no known cause of cancer in adults and children. However, considering the patterns evidenced in many countries, the causes in adults are attributed in lifestyle or environmental risk factors such as smoking, foods eaten, inhaling chemicals, exposure to natural and synthetic radiations (Peto, 1996 as cited in Auyang, "n.d", p. 5). However, the case is different in children as it is usually the result of changes in their DNA that could even happen during conception (American Cancer Society, 2013, What are the differences between cancer in adults and children? section, para. 1; Fearon, "n.d" as cited in Auyang, "n.d", p. 5).

There are different types of cancer that affect children. Leukemia, also referred as blood cancer, affects the bone marrow causing anemia, bleeding and infections. Another type of cancer is Hodgkin's disease which originate in a single lymph node or a single chain of nodes and metastasizes to spleen, liver bone marrow and lungs. Wilms' tumor, cancer of intra-abdominal and kidney, is another type of childhood cancer. Osteogenic sarcoma is the most common type of bone cancer in children. Brain tumor and neuroblastoma are also other types of cancers that affect children (Silverstri, 2008, pp.548-554; Children's Oncology Group, 2011, pp. 13-26; Kramárová & Stiller, 1996, pp. 759-761).

The serious health problems caused by cancer ranges from impaired immune and blood producing functions, altered gastro-intestinal tract structure and function, motor and sensory deficits to decreased respiratory function with death as the fatal consequence (Silverstri, 2008, p.635). According to Shad, Challinor and Cohen (2013, p. 109) in Ethiopia, mortality rate for majority of childhood cancers is close to 100% even for the most treatable forms of childhood cancer.

2.1.2. Cancer Treatment and Side Effects

Chronic diseases in children are substantial due to the fact that they occur at a stage where the ordinary course of a child's development is affected making the care tremendously complex and involving a combination of medical and other services (Stein, 2001 as cited in Australian Institute of Health and Welfare, 2005, p. 3).

The treatment of cancer involves surgery, chemotherapy and radiotherapy. In some cases, two or three of the treatments are combined. For cancer treatment, surgery is provided as prophylactic, curative, controlling, palliative, reconstructive means. The different types of surgeries serve different purposes for instance prophylactic surgery is performed to remove an existing premalignant tumor to prevent it from turning into malignant tumor. On the other hand, curative surgery is performed to remove a malignant tumor and controlling surgery is performed to control the number of cancer cells to increase the chance of other treatments working. Palliative surgery is performed to reduce pain, relieve obstructions and others so as to perk up quality of life. Similarly, reconstructive surgery is also performed to improve quality of life through reinstating maximum function and appearances (Silverstri, 2008, p.638).

The other treatment type is chemotherapy which is used destroy or halt the reproduction of cancer cells at the same time destroying normal cells. Chemotherapy agents are administered systematically and sometimes different agents are combined to "increase the therapeutic response" (Silverstri, 2008, p.638). Radiotherapy on the other hand is used to kill cancer cells with minimum exposure and damage to normal cells leading to inhibition of the replication ability of the cancer cells or kill the attacked cells (Silverstri, 2008, p. 639).

Cancer treatment is not without side effects. Chemotherapies and radiotherapies have side effects of fatigue, alopecia (hair loss), nausea, vomiting, mucosities, skin changes, bone marrow suppression (neutropenia, anemia, thrombocytopenia), fever, pain, skin changes, irritation, sleeplessness, changes in eating and sleeping patterns, changes in attitude, mood and behavior, distress, suffering and changes in taste sensation on individuals taking the treatment (Silverstri, 2008, pp.638-639; Jones, 2012, p. 217). Although, children tend to respond to chemotherapeutic medications better than adults, children who had taken the treatment require careful follow-up for the reminder of their lives as both (chemotherapy and radiotherapy) treatments are known to have long-term side effects (American Cancer Society, 2013, What are the differences between cancer in adults and children? section, para. 2).

2.2. Impact of Cancer on Children, Siblings and Parents

The diagnosis of a child with cancer, despite its prognosis, brings tremendous impact on the child, the parents, siblings and other family members (Jones, 2012, p. 214). In line with that, this section of the chapter presents literatures that discuss the different arenas of those impacts.

2.2.1. Impacts to Diagnosed Children

The most commonly used definition of health is that of WHO that considers health as "a state of complete physical, mental and social wellbeing and not merely the absence of a disease infirmity" (WHO, 1949 as cited in WHO, 2003). According to Lucas and Lloyd (2005, p.6), WHO's definition advocates for consideration of not a in a healthy state for anyone "with the slightest imperfection in their bodily, psychological or social functioning". In that notion, as cancer in children has profound psychological, social and physical impact (Li, Chung & Chiu, 2010 as cited in Marcus, 2012 p. 211) although children's reaction to the diagnosis and treatment varies depending on personality traits, age, social attitudes, and child's relationship with the parents and other factors (Chalikiopoulou, 1980 as cited in Theofanidis, 2007, p. 2).

From psychological perspective, children experience shock, stress, fear, anxiety, anger, guilt, sorrow, depression, low self-esteem, negative perception of self-appearance among other things (Theofanidis, 2007, p. 1; American Cancer Society 2012, How do children with cancer and their siblings react to a cancer diagnosis? section, para. 9; Toro, "n.d", The psychological impact on the child section, para. 1). The different psychological experiences that children exhibit are due to inter related aspects of the disease and affiliated diagnosis and treatments. In line with that, McCaffery (2008), argue that children diagnosed with cancer encounter stress as a result of the treatments they undergo and also have problems coping (as cited in Marcus, 2012 p. 211). Similarly, Theofanidis (2007, p. 1) and American Cancer Society (2012, How do children with cancer and their siblings react to a cancer diagnosis?, para. 10) state that children diagnosed with cancer are afraid of the sudden shift from a normal state to being sick as well as to the different invasive tests and treatments associated such as bone marrow aspiration, lumbar puncture, frequent blood withdrawals and others. They also develop fear when they view that the existing circumstances as permanent which in some instances may lead to panic state that will "influence their ability to deal with the symptoms and to learn ways of coping on a physical and psychological level" (Theofanidis, 2007, p. 2).

Anger and guilt are normal experiences of children. The anger is related to the different procedures they have to do, have their privacy be invaded and being admitted to the hospital for a longer period at times (American Cancer Society, 2012, Siblings of the child with cancer section, para. 2). And the guilt usually arises from their belief that the situation is a "punishment" for being "bad" or "parents past sins" (American Cancer Society, 2012, How do children with cancer and their siblings react to a cancer diagnosis?, para. 11; Theofanidis, 2007, pp. 1-2). The guilt exacerbates especially when the family encounters crisis, when parents are in conflict or even divorce (American Cancer Society, 2012, How do children with cancer and their siblings react to a cancer diagnosis? section, para. 13).

The other feelings that children with cancer encounter are sadness and depression. Realization that some of the routine activities and those they enjoy doing will be halted for a long time and that they are not the same anymore leads to their feelings of sadness. On top of that, their perception in how their friends see them and how their body is changing causes them depression (American Cancer Society, 2012, How do children with cancer and their siblings react to a cancer diagnosis? section, para. 16).

In addition to psychological impacts children experience arising from the physical symptom of cancer and treatments associated, they also experience severe social challenges and behavioural disturbances (Toro, "n.d", The psychological impact on the child section, para. 1; Chalikiopoulou 1990 as cited in Theofanidis, 2007, p. 2). In addition, they also tend to develop low self-esteem, negative perception of self-appearance, and insecurity that in one form or another affects their interaction with their peers and their families (Theofanidis, 2007, p. 1; Toro, "n.d", The psychological impact on the child section, para. 3; Chalikiopoulou, 1990 as cited in Theofanidis, 2007, p. 2). According to Toro ("n.d", The psychological impact on the child section, para. 2), having to go through the different challenges of cancer such as "pain, hair loss, weight gain or loss, physical disfigurement, and repeated absences from school and peers" severely affects their psychological and social adjustment. In addition to that, the insecurity they feel also escalates parental stress that will in turn further increase the stress of the children and may even bring behavioral disturbances (Chalikiopoulou 1990 as cited in Theofanidis, 2007, p. 2).

2.2.2. Impact of Cancer on Siblings of Children with Cancer

As previously mentioned, diagnosis of a child in a family has effect on the whole family including siblings of the diagnosed child. Similar to children diagnosed with cancer, their siblings are also challenged psychologically and socially.

As the families' daily routines and normal activities change, the routines siblings used to also change to the extent of being cared for by relatives or neighbors (American Cancer Society, 2012, When a child has cancer, it's a crisis for the whole family section, para. 1). As a result, according to Toro ("n.d", The psychological impact on the family/caregiver section, para. 2), siblings feel "anxious, stressed, overwhelmed, neglected and guilt". In addition to that, they also experience greater distress, post-traumatic stress symptoms, negative emotional reactions, poor quality of life, a sense of losing parental attention and sense of status in the family (Alderfer, Long, Lown, et al. 2010 as cited in Jones 2012, p. 216). To the contrary, some siblings also show positive outcomes such as increased capacity for empathy and psychological maturity (Alderfer, Long, Lown, et al. 2010 as cited in Jones 2012, p. 216).

According to American Cancer Society (2012, How do children with cancer and their siblings react to a cancer diagnosis? section, para. 11), siblings of children with cancer are fearful of the situation that they have no idea what it is but something is wrong with their brother or sister and that they may also get cancer. And the fact that their parents are not there to care for them while other family members, neighbors and family anxiety, depression, prolonged and complicated mourning are among the potential adverse consequences for parents with children diagnosed with cancer (as cited in Jones, 2012, p. 214).

The different emotions exhibited by parents arise as a consequence of different issues related to their child's diagnosis. According to American Cancer Society (2012, How do parents usually react to a child's cancer diagnosis? section, para. 2) when parents first hear their child's diagnosis, they may be frightened that their child "is going to suffer and perhaps die", they also feel confused and experience numbness which they describe as inability to hear when physicians explain the child's diagnosis or plan of treatment. In support of the notion, a study by Khoury, Huijer and Doumit (2013, p. 20) had revealed that almost all study participants had experienced shock when their child was diagnosed with cancer and had lead to losing their "way of life".

Furthermore, disbelief and denial are also common feelings parents experience manifested by questioning whether laboratory had made a mistake, if the result actually belong to their child, seeking to get second opinion, questioning the qualifications medical staffs or health facility (American Cancer Society, 2012, How do parents usually react to a child's cancer diagnosis? section, para. 4). On top of that, fear and anxiety usually arises from being bombarded by an unfamiliar situation and the result of which cannot be controlled, stories heard about the problems others encountered due to treatment or beliefs that cancer is equivalent of 'a death sentence' (American Cancer Society, 2012, How do parents usually react to a child's cancer diagnosis? section, para. 7).

friends are taking care of them (American Cancer Society, 2012, How do children with cancer and their siblings react to a cancer diagnosis? section, para. 11). Another emotional reaction common among siblings is anger which arises as parent's focus and attention is directed towards the sick child, they feel that their parents have no time for them and the routines they were used is changing (American Cancer Society, 2012, How do children with cancer and their siblings react to a cancer diagnosis? section, para. 14). Similarly, in a study conducted by Khoury, Huijer and Doumit (2013, pp. 19-20) revealed that sibling rivalry as one issue parents needed to deal with as a result of their focus and attention being directed towards their sick child.

2.2.3. Impact on Parents with Children Diagnosed with Cancer

Parents experience different psychological, social and physical challenges in relation to their child's diagnosis with cancer. Accordingly, this section presents what different literatures and researches state about the impacts parents face as a result of their child being diagnosed with cancer.

2.2.3.1. Psychological Impacts

When parents hear the diagnosis of their child, they experience emotions of shock, disbelief, anger, fear, guilt, sadness and anxiety (American Cancer Society, 2012, How do parents usually react to a child's cancer diagnosis? section, para. 1). Similarly, Children's Oncology Group (2011, pp. 92-93) and Jones (2006 as cited in Jones, 2012, p. 214) also share the notion that most parents feel hopeless, become depressed, feel sense of dishonest and blame themselves for their child's sickness and think always about what may have caused their child's cancer leading to diverse personal and social life problems. However, for Manne, Duhamel and Redd (2000), Jones (2006) and Boman (2003)

Parents guilt arise especially after accepting the diagnosis of their child evident through feeling they may have done something to cause their child's sickness, feel it could be "payback" for their past mistakes. Mothers mostly feel guilty associating the situation with something they did or failed to do so during their pregnancy (American Cancer Society, 2012, How do parents usually react to a child's cancer diagnosis? section, para. 10). Sadness and depression are other emotions experienced by parents with a child with cancer as the hopes and dreams they had for their child is shattered due to the diagnosis of the disease leading to feeling of sadness and hopeless (American Cancer Society, 2012, How do parents usually react to a child's cancer diagnosis? section, para. 15).

Parents ask "Why me?" or "Why us?" and feel angry towards the cruel and random injustice of life due to their child's health situation. Their anger could be directed towards health professionals involved in their child's care, the painful diagnostic and treatment procedures, staying at the hospital for long periods of time, to other family members and friends for lack of support and for thoughtless remarks. In some instances, parents may even resent one another as well for previous or current situations that are affecting their child's treatment (American Cancer Society, 2012, How do parents usually react to a child's cancer diagnosis? section, para. 19).

2.2.3.2. Social Impacts

Chronic illnesses including cancer have several social impacts on parents when their child is diagnosed with one including change of family roles, addition of responsibilities, marital disruptions, change in quality of life and economic impacts (Jones, 2012, p. 215; Khoury, Huijer & Doumit, 2013, pp. 18-19; Bona, Dussel, Orellana, Kang, Geyer, Feudtner & Wolfe, 2014, p. 598). Similarly, for Manne, Duhamel and Redd (2000), financial distress, marital/partner or family discord, social and behavioral problems for the child and/ or their siblings are among the potential adverse consequences parents with children diagnosed with cancer encounter (as cited in Jones, 2012, p. 214).

In regards to role changes, parents have a nurturing role to their children which is altered with the diagnosis of their child with cancer. The nurturing role that parents are well acquainted with adds the role of "advocates, councilors, and medical technicians" and they begin to deal with and respond to different side effects of treatments involved when their child has cancer (Jones, 2012, p. 215). In line with that, the findings of Khoury, Huijer and Doumit (2013, p. 19) reveals that the diagnosis of a child with cancer adds responsibilities to both parents with the fathers being financially responsible and mothers with taking care of the household.

Similarly, studies by Young, Dixon-Woods, Findlay et al. (2002) and Jones, Pelletier, Deeker, et al. (2010 as cited in Jones 2012, p. 216) had revealed that burden of responsibilities differ from one parent to the other as in many families, mothers are at the bedside of their child while fathers return to work and focus on the financial aspects. When the role responsibilities split between the parents, the impacts also differ as fathers report feeling of distant and uninformed about the care and treatment of their child while mothers report the emotional work of care giving as intense and complex (Young, Dixon-Woods, Findlay et al., 2002 & Jones, Pelletier, Deeker et al., 2010 as cited in Jones 2012, p. 216).

Another social impact observed in parents with a child with cancer is marital problems. Some studies attribute that parents experience marital problems when they have a child with a chronic illness including lack of time with each other, communication problems, conflict, increased role strain, decreased relationship satisfaction and divorce (Lawrence, 2012, p. 21; Brody & Simmons, 2007; Da Silva et al., 2010; Yeh, 2003 as cited in Khoury, Huijer and Doumit, 2013, p. 20). In contrast to that, other studies have found out no effect while others have indicated "increased closeness, greater cohesion, increased support and lower divorce rates" among spouses (Lawrence, 2012, p. 21). Similar to both notions, a study by Khoury, Huijer and Doumit (2013, p. 20) had found out that in most families in their study, child's illness had brought cohesion and closeness among the couple while in one family the couple's relationship was filled with conflict.

In relation to social interaction, Pollock, Litzelman, Wisk and Witt (2013, p. 107) had found out that parents of children exhibited greater negative social interactions significantly. Adding to that, Patterson and McCubbin (1983), Byrne and Cunningham (1985) and Kazak (1986) state that "families with a child with a chronic illness have been described as socially isolated from formal and informal sources of support" (as cited in Tak & McCubbin, 2002, p. 192). Similarly, a research by Velde, Demares, De Vos, De Porre, Moerloose, Benoit and Veleye (2011) had identified that some parents opened and wrote on weblogs due to the isolation they had felt while most to share firsthand information about their child with families and friends. The researchers have also found out that blogs were being used as a venting means for parents and had also helped parents in receiving social and emotional support from other parents in the same situation (as cited in European Journal of Oncology Nursing, 2011, p. 275).

Another social impact parents have to deal with is economic problems secondary to their child being diagnosed with cancer that includes financial burden, work disruption and leaving job and in some cases terminating treatment as a result of inability to afford treatments. A study conducted by Bona, et al. (2014, p. 598) that looked into the economic impact of advanced childhood cancer on families had found out that prevalent work disruption of parents (94% families) across all income levels, at least one parent leaving a job due to child's illness in 42% families and loss of income due to work disruptions which is considerable in all families. In the same study, more than 28% of parents portrayed their child's illness as "a great economic hardship" (Bona, et al., 2014, p. 597). Similarly, a study by Khoury, Huijer and Doumit (2013, p. 19) had also identified financial issues in cancer treatment of children to be an issue among Lebanese parents. In the study, one father had stated that one of his sons had to drop out of university and his daughter had to transfer to public school because the family was not able to afford paying as the medical expense of their sick child was massive and his salary was not sufficient (Khoury, Huijer & Doumit, 2013 p. 19).

In Ethiopia context, the findings of a study conducted by Alemayehu Hailu and Damene Hailemariam (2011, pp. 3-4) had showed that 'the mean outpatient cost' incurred by a single cervical cancer patient to be $407.20 while that of the inpatient was $334.20 with 74% of the cost related to medical while 26% related to non-medical costs. In line with that, the researchers had concluded that cervical cancer presents enormous financial burden on patients and families (Alemayehu Hailu & Damene Hailemariam, 2011, p. 7).

2.2.3.3. Physical Impacts

Parents with a child diagnosed with cancer exhibit different physical challenges due to their child's illness as the burden of taking care of their sick child is immense that they tend to neglect their own health and well-being (Acton GJ, 2002 as cited in Klassen, Klaassen, Dix, Pritchard, Yanofsky, O'Donnell, Scott, and Sung, 2008, p. 5884). Similarly American Cancer Society (2012, Ways to improve coping section, para. 3) also asserts that parents caring for their child diagnosed with cancer tend to neglect routines such as "eating, sleeping, exercising, and taking breaks from caring for the child" which are important for parents as it will enable them to care for their child better and are assurances to the sick child that some routines are maintained and parents are well. Not only neglecting the daily routines, parents also experience difficulty of eating and sleeping and lack energy to conduct their daily tasks (American Cancer Society, 2012, How do parents usually react to a child's cancer diagnosis? section, para. 15).

A study conducted by Klassen et al. (2008, p. 5884) tried to look into "health-promoting self-care actions, such as getting enough rest, eating nutritiously, and getting enough exercise" in parents of children with cancer. And the findings show that parents of children with cancer in the sample group reported considerable lower quality of life than the population norm (Klassen et al., 2008, p.5887). Even though there were difference in quality of life between the research sample and population norms in all domains and scores, the researchers had found an exception to difference on the physical function and physical component score (PCS) (Klassen et al., 2008, p. 5887). In addition to that, the study also revealed that there is a strong relationship between sleep quality and quality of life (Klassen et al., 2008, p. 5888) which support the notion that "sleep problems are prevalent in cancer populations" (Clark, Cunningham, McMillan, et al., 2004; Vena, Parker, Cunningham, et al., 2004; Berger, Parker, Young-McCaughan, et al., 2005 as cited in Klassen et al., 2008, p. 5888). According to Boman, Lindahl and Bjork (2003), Viksten, et al. (2004), Ferrell, et al. (1994), and Gedaly-Duff, et al. (2006), sleep disturbances are common among parents of children with cancer (as cited in Klassen et al., 2008, p. 5888). Similarly, a research by Pollock, Litzelman, Wisk and Witt (2013, p. 107) had found out that parents of children with cancer exhibited poor quality of sleep associated with the stress level parents were in. Likewise, according to, Meltzer and Moore (2008, p. 279), "nighttime care giving, and/or worries about the child's illness, can result in sleep disruptions; including poor sleep quality and shorter sleep quantity for parents".

In addition to stress levels and other related factors affecting parents, the conditions under which they sleep also has profound effect. In accordance to that, a study conducted by Young, Dixon-Woods, Findlay and Heney (2002, p.1838) had found out that mothers of children with cancer, when their children are admitted to the hospital "usually slept in camp beds at their children's bedside in open wards in cramped conditions with lack of privacy and difficulties in sleeping". Moreover, Brehaut et al. (2004) and Raina et al. (2005) state that parents of children with chronic illness are prone to poor health condition as compared with those who have health children (as cited in Meltzer & Moore, 2008, p. 279).

2.3. Parental Coping Mechanisms

Parents of children diagnosed with cancer utilize different mechanisms to cope with the psychosocial problems caused due to their child's diagnosis with cancer which depends on the time and severity of the illness (Hamama-Raz, Rot and Buchbinder, 2012, p. 34). Coping, as defined by Hutchison (1999, p. 138), is "our efforts to master the demands of stress, and includes the thoughts, feelings, and actions that constitute these efforts".

2.3.1. Parents own coping mechanism

In line with that, Hutchison (1999, p. 141) identified two methods by which individuals try to cope during incidences, problem-focused or emotion-focused. In problem-focused coping style, people view that circumstance could be restrained so they try to alter the circumstances by taking actions. To the contrary, emotion-focused coping, prevails in situations that are viewed unchangeable, people try to cope either by amending the manner by which the circumstance is tended or by changing the "meaning to one self of what is happening" (Hutchison, 1999, p. 141).

Similarly, a study by Papastavrou, Charalambous and Tsangari (2012, p. 260) had identified the different copying strategies utilized by care givers. According to the findings of the study, positive approach, seeking social support, wishful thinking, avoidance/denial, confronting coping, burden and depression were identified as coping strategies utilized by care givers. The study had also found out that majority of participant care givers used emotionally focused, that is avoidance or denial, and wishful thinking, coping strategies (Papastavrou, Charalambous & Tsangari, 2012, p. 261). Accordingly, statements such as "I was hoping for a miracle", "I was hoping that time would change things and simply waited" and "I found consolidation in my faith to God" were emotionally focused ways of coping that were repeatedly used with the highest mean (Papastavrou, Charalambous & Tsangari, 2012, p. 260). To the contrary, "I expressed my anger to the patient", "I dared to do something risky" were statement that were used by care givers with lowest mean (Papastavrou, Charalambous & Tsangari, 2012, p. 260).

Similarly, Norberg, Lindblad and Boman (2005, p. 970) had conducted a study to identify the coping strategies utilized by parents of children with cancer and identified that among parents, there is "more frequent tendency to use passive reaction pattern that is, isolating from others, escaping into fantasies". The study had also revealed that more frequent use of "active problem focusing (acting immediately and being goal oriented, sorting things out) rather than avoidance behavior (drawing back from problematic situations) and passive reactions were associated with low levels of anxiety and depression" (Norberg, Lindblad & Boman, 2005, p. 970). Likewise, in coping with the challenges of financial burden, Bona et al. (2014, p, 598) had found out that all families in their study had utilized similar strategies to pay for medical care including "reducing expenses by avoiding big purchases, incurring debt, selling property and organizing fundraising" (Bona et al., 2014, p. 598) which corresponds with active problem focused coping strategy. Other coping mechanisms utilized by parents that Norberg, Lindblad and Boman (2005, pp. 970-971) had identified were "palliative reaction (engaging in other activities, trying to relax) and expressing emotions (expressing annoyance and anger)".

2.3.2. Supports that assist parents to cope

American Cancer Society (2012, Ways to improve coping section, para. 1) recommends different supports that will enable parents to cope better with their child's illness. In line with that, Hamama-Raz, Rot and Buchbinder (2012, p. 37) stress on utilization of formal and informal supports as ways in which parents cope with the social problems they encounter. The formal support system is from health care professionals and treatment centers or hospitals through provision of medical support to their child. Whereas, informal social supports are from the couples themselves, family and social networks (Hamama-Raz, Rot and Buchbinder, 2012, pp. 36-37).

For parents support from health professions or "cancer team" such as doctors, nurses, social workers and others involved through information provision, counseling, teaching "new skills such as relaxation and stress management" (American Cancer Society, 2012, Ways to improve coping section, para. 2). Similarly, a study conducted by Hamama-Raz, Rot and Buchbinder (2012, pp. 26-27) on the experience of parents with a child with retinoblastoma (cancer of the eye) in coping had found out that parents began the journey of coping when they had received the definite diagnosis of their child. Similarly, the researchers assert that providing parents with clear information on medical diagnosis and treatment plan of their child is an important step is assisting them to cope with the challenges (Hamama-Raz, Rot and Buchbinder, 2012, p. 36). Correspondingly, Kästel, Enskär and Björk (2011, p. 291) states that clear information should be provided to parents on the diagnosis and treatment of their child as it will assist them in taking responsibility and making decisions. On the same note, Hamama-Raz, Rot and Buchbinder (2012, p. 35) had found out that the different emotions parents initially feel when their child was sick such as helplessness, panic, and fear were exacerbated by parents receiving vague information from health professionals.

Another mechanism that will assist parents to cope with the impacts of childhood cancer is communication among the couple. According to Da Silva, Jacob and

2.4. Theories and Models

This study considers bio-psychosocial model and family stress theory in trying to understand the psychosocial impact of childhood cancer on parents and their coping mechanisms. The following section tries to discuss the basic principles of the two in relation to the study topic.

2.4.1. Bio-Psychosocial Model

The bio-psychosocial model is an" integrated approach to human behavior and disease" (Dogar, 2007, p. 11) that emphases on the interaction of the biological, psychological and social aspects of an individual as a determinant factor in health and wellbeing. The model encompasses family and community and also emphasizes on prevention of illness and promotion of health as much as on treatment of disease (Dogar, 2007, p. 11). Similarly, referring to the works of House, Landis and Um'bBrson (1988), Levine, Coe and Wiener (1989) and Weitz (1996), Hutchison (1999, p. 85) argues that there exists a relationship between physical, psychological health and social experiences which are well evidenced and backed with "strong conceptual, theoretical and empirical evidence".

In regards to health of individual, Lowe (1997) recommends not to view health as an experience specific only to an individual but within the framework of the community, group, and organization (as cited in Hutchison, 1999, p. 85) which is common in the healthcare system, where bio-medical model takes precedence, integrated mind and body treatment tend lack (Sperry, 2006, as cited in Atkinsa, Colville & John, 2012, p. 134). On the same note, Lowe (1997) encourages on the use of models that "seek to promote the health of communities as well as empowering individuals, families, and groups to advocate for their own health needs" in social work practice (as cited in Hutchison, 1999, p. 85).

2.4.2. Family Stress Theory

The family stress theory asserts that any event (stressor), positive or negative, will have an impact on families. Grounded in the ABC-X model, the theory's basic assumption asserts that coping or get into crisis with a situation depends on how the family perceives or defines that event (Smith, Hamon, Ingolsby, Miller, 2009, pp. 96-97).

Correspondingly, Lipman-Bluman (1975) state that the degree to which a stressor will impact a family and their ability to cope depends:

> whether the stressor being internal or external to the family, stressor focused on one family member or on all family members, suddenness or gradual onset of the stressor, severity of the stressor, the length of time it would take family members to adjust to a stressor, whether it is expected or not, natural or artificial, and the family's perception of whether or not they are able to solve situation (as cited in Smith, et al., 2009, pp. 96-97).

The theory also asserts that families can cope with a stressor event through utilizing resources available which could be within individuals in the family, friends and other family members, and from the community (Smith, et al., 2009, pp. 96-97). According to McCubbin and Patterson (1985), resources are of individual, family, and community. Hence, the utilization of a variety of resources brings about a good response against stress (as cited in Smith, et al., 2009, pp. 96-97). Similarly, McKenry and Price (2000) assert that social support is one of the most important resources that could be accessed which may be provided through families "instrumentally, emotionally, and through the building of increased social networks" and from community "increased networking, help with problem-solving skills, and providing assistance in accessing valuable resources" (as cited in Smith et al., 2009, pp. 96-97) as support enables one to build self-esteem and feelings of self-worth increase and can be seen as a sign of love" (Smith, et al., 2009, pp. 96-97). In addition to that for Smith et al. (2009, pp. 96-97), "good social support from friends, neighbors, and family can lead to more positive change and can minimize the effects of environmental stress".

CHAPTER THREE: RESEARCH METHOD

This chapter presents the research method employed in conducting the study. It presents the study design employed with justifications. The method is a descriptive qualitative research with case study as its strategy of inquiry. Purposive sampling technique was used to select participants. As primary source of data collection, interview guides were used. The chapter also presents study area, participant selection and sampling methods utilized. In addition, it also contains data collection procedure, data analysis and data quality assurances employed. Lastly, ethical consideration aspects of the study are presented.

3.1. Study Design

Alston and Bowles (2003, pp. 65-66) describe research design as a road map for data collection, analysis and how it is reported including the progression in sampling, data collection methods and analysis to be used. However, in order to select the appropriate research design for a study, a researcher must have a clear philosophical worldview or stance. According to Creswell (2014, pp. 5-6), philosophical worldview or stance of a research will explain the choice for the type of methods of approach in a research.

In line with that, the philosophical worldview that was selected to guide this research was social constructivists. According to Creswell (2014, p.8), social constructivist worldview give space for individuals to try and search their own understanding of the world they live in and extract their own meanings which could be diverse and numerous and in turn will enable researchers to look into the "complexity of views" instead of contracting meanings "into few categories or ideas and make sense of" these meanings.

As the objective of the study was to identify the psychosocial impact of childhood cancer on parents with children diagnosed with the disease and how they cope with the challenges they are faced with, it was the parent's point of view and their meanings to the situation that was sought and studied. The goal of the study was finding out parent's interpretation and understanding of their own situation due to their children's illness. As a result, social constructivist view had guided the research design in trying to gather the required information for the study.

After identifying the philosophical stance, two dimensions had been considered related to time and purpose of the study. With regards to time dimension, the study was a cross-sectional research looking into the psychosocial impact childhood cancer has on parents and how they cope at a single point of time. Although cross-sectional research has shortcoming in "not capturing social processes" (Krueger & Neuman, 2006, p.32), "has the disadvantage of not being able to capture social processes or change", it was chosen in this study because participants are from target population group that are hard to trace and coming from all parts of the country to one center. In addition to that, it was selected as it is less costly and less time taking

As the purpose of the research is to describe the psychosocial impact of childhood cancer on parents with children diagnosed with the disease and parents coping mechanism, descriptive research had been selected as it tries to show a picture of the precise details of a "situation, social setting, or relationship" (Krueger & Neuman, 2006, p.22). Therefore, this study had tried to show the details of the psychosocial impact childhood cancer brings on parents and how they try to cope.

The research method chosen for this study is qualitative research method. As Monette, Sullivan and Dejond (1994, p. 82) put forth, the state of our knowledge on a certain research topic directs our choice for the method. In case of this study, there is lack of knowledge and research in the area of psychosocial impact of childhood cancer on parents with children diagnosed with the disease and their coping mechanisms in Ethiopia. For that reason, qualitative research method was chosen. On top of that, qualitative research method was chosen as it enables to gain "complex and detailed understanding", according to Creswell (2007, p.40), on the topic of interest.

In order to gain an in-depth and detailed information on the topic of interest, the study used collective case study method that enabled researchers to take in a single issue and conduct multiple cases to demonstrate the issue (Creswell, 2007, p. 74) and as it will assist in gaining detailed insight into the issue, as Yin (2003, p.2) describes, "a holistic and meaningful characteristics of real-life events". In accordance with the research design selected, non-probability sampling, specifically purposive sampling was used to identify participants and collect data.

3.1.1. Study Setting

As the study focuses on the psychosocial impact of childhood cancer on parents with children diagnosed with cancer, the study setting is Tikur Anbessa Specialized Hospital (TASH), Addis Ababa. Established in 1973, TASH is the only compressive cancer care and treatment center for both children and adults' in Ethiopia. In regards to childhood cancer, TASH is the only referral cancer diagnostic and treatment centre in Ethiopia providing service for children from all parts of the country. The pediatrics department of TASH is located on the seventh floor of the main building. It has its own dedicated Pediatrics Hematology/Oncology ward providing service for children diagnosed with cancer at inpatient (admitted in the ward for diagnostic or treatment) and outpatient (staying at home or a shelter and following treatment) levels.

Therefore, the rational for selecting the study area arises from the fact that TASH is the only cancer diagnostic and treatment center providing service for children from all parts of Ethiopia.

3.2. Selection of Study Participants

As Krueger and Neuman (2006, p. 209) stated, qualitative research focuses on how the samples present the issue in a way that clarify and expand understanding of the subject. As the study was trying to seek information in the area of psychosocial impact of childhood cancer on parents and the expected participants were parents with children diagnosed with cancer, the study had utilized non-probability sampling to select participants that could assist in acquiring detailed information on the research topic. In line with that, Alston and Bowles (2003, p. 87) had stated that when a research is in quest of information in an original area and focuses on participants who symbolize the topic under study, non-probability sampling is very valuable.

Of non-probability sampling, purposive sampling was used to select participants who had provided in-depth information about the research issue. A professional nurse working in the ward had helped me in identifying participants for the fact that I needed a professional to identify those parents whose children with cancer as there were also parents whose children's status were not confirmed. The nurse identified the participants from and gave me a list and I approached participants myself and used the exclusion and inclusion criteria's set for this study to further refine participants.

3.2.1. Sample Size

The qualitative research, according Krueger and Neuman (2006, p. 209) and Creswell (2014, p. 189), does not require sample sizes or participant number to be determined in advance. Morse (1994) also asserts the same notion and emphasizes on attaining adequate information rather than focusing on the number of data collected (as cited in Krueger & Neuman, 2006, p. 434). However, Creswell (2014, p. 189) recommends incorporating four to five participants when employing case study method. In consideration of all the factors, this study had conducted in-depth face to face interview with eight individual parents of children diagnosed with cancer.

On top of that, focus group discussion was included in the study. Both Creswell (2014, p. 190) and Kerr et al. (1998 as cited in Bloor & Wood, 2006, p. 89) recommends maintaining participants number in focus group in the range of six to eight in order to gain in-depth detailed information on the topic. Similarly, the study had conducted interviews with a single homogeneous focus group comprising of fathers. The participant's number in the group comprised of eight individuals.

In addition to direct participants, three health care professionals who are working at the pediatrics hematology/oncology unit of TASH were also included as key informants. Therefore, a total of nineteen people have participated in the study.

3.2.2. Inclusion and Exclusion Criteria

As the focus of the study is on psychosocial impact of childhood cancer on parents with children diagnosed with the disease, the main participants of the study were willing parents of children diagnosed with cancer and following up treatments either admitted or as outpatients at the pediatrics hematology/oncology unit of TASH. To the contrary, parents of children with other chronic diseases, parents who have not been informed of their child's diagnosis by a physician and parents of children who were in critical condition during time of data collection were excluded from participating in the study.

The study had also incorporate in-depth interview with three health care professionals (nurses and physician) who are working and have been engaged in providing treatment for cancer patients at the pediatrics hematology/oncology unit of TASH. These key informants were included in the study to provide additional perspective to the issue under study.

3.3. Methods of data collection

Creswell (2009, p.179) stated that qualitative research depends on multiple sources of data to obtain a comprehensive understanding of the research issue. To acquire primary data, face to face interviews in the form of in-depth and focus group interviews with parents of children diagnosed with cancer were conducted. In addition to that, in-depth interview was conducted with health care professionals as key informants. The study also used observation as a method of data collection. Other sources of data that were used to obtain information was reviewing public documents relevant to the topic of study including books, journals, magazines, newspapers, booklets, brochures, and websites.

In-depth Interview

According to Alston and Bowles (2003, p.117), in-depth interview was selected as it is more flexible than other methods of collecting data, provides participants the space to freely respond to the study topic and allows researchers to conduct the interview themselves which is one way assuring quality of collected data. The researcher used semi-structured open ended questions as it gives participants the opportunities to freely share their views and experiences. In order to get detailed information, efforts have been made to use probing questions as needed in-between the open ended questions (see annexes 2 & 6). The interview guide was developed in accordance with issues assessed in literature review section and from the research questions.

In conducting the interview, Amharic was the medium of language with seven participants. And with one participant, I had used a translator, based on the consent given by the participant, as the participant was bi-lingual (speaks Amharic and Oromifa). In interviewing the participant, I asked the questions in Amharic and for most parts he did not needed a translator to translate the questions but in areas that needed further clarification, the translator was used. The participant, when he felt comfortable, responded in Amharic but for most parts he was responding in Oromifa which was translated to Amharic by the translator. The interviews were conducted in a quiet room in the ward allocated for this study taking an average of forty to sixty minutes. And all the interviews conducted were audio recorded and notes were also taken during the interviews.

Focus Group Discussion (FGD)

Focus group interview allows researchers to gain further insight into the study topic when different people who are knowledgeable in the topic are involved (Alston & Bowles, 2003, p. 119). Moreover, Bloor and Wood (2006, p. 89), Alston and Bowles (2003, p. 119), and Krueger and Neuman (2006, p. 286) recommend that focus groups to be homogenous to be able to decrease conflict while at the same time ensuring that participants are not relatives or friends.

In line with that, primarily, it was planned to conduct two focus group discussions comprising of mothers in one group and fathers in the other to get different perspectives on the issues. However, focus group discussion with mothers was not conducted as the number of mother participants acquired was less than the minimum number of participants needed for the discussion. The reduction in the number of participants was as a result of some identified mothers were not provided medical counseling and were not informed of their respective children's status while others were mothers of newly admitted children for diagnostic purposes. As a result of that, the identified participants were taken off from the study.

Nevertheless, focus group with a homogenous group comprising of eight fathers was conducted. The discussion was conducted with the support of open ended questions and probing and further clarification rising questions were used (see annexes 3 & 7). On top of that, efforts were made to receive the opinions of all participants through guiding the discussion and using diverting questions. The interview guide that was used for the discussion was developed in accordance with issues assessed in literature review section and from the research questions.

The medium of conversation during the focus group discussion was Amharic and Oromifa. All participants could listen and speak in Amharic. However, three participants were comfortable to speak in their native language which was Oromifa. For that purpose, I had used translator with the consent of all the participants. The discussion took place in a quiet room in the ward and took an hour and forty five minutes. Questions were asked in Amharic and they were translated to Oromifa language and responses from participants were translated in Amahric and were transcribed later.

Key Informant Interview

Key informant interview was also conducted with three health care professionals of Pediatrics Hematology/Oncology unit. Two of the participants were nurses, one head nurse and the other staff nurse of the ward, while the third key informant was a physician who is the head of the unit and senior physician for children diagnosed with cancer. Semi-structured questions were used as a tool of data collection to look into formal services available in the hospital for parents and the progress in childhood cancer care and treatment (see annex 4). The participants had given verbal consent prior to conducting the interview.

Observation

Another source that was employed in collecting data in this study was observing participant's behaviors, gestures and actions involved in the study as it enables researchers to gain "firsthand experience", document information on the spot, notice odd occurrences and look into issues that may be uncomfortable for participants (Creswell, 2014, p. 191). While conducting the in-depth interviews, participant's behaviors, gestures and actions were observed and notes were taken on the spot that were used during data analysis.

On top of that, observation of the ward set up as well as when activities such as children's play and coffee ceremony were conducted so that I can be familiar with the environment and gain firsthand information with utilization of unstructured observation technique.

3.4. Data Analysis

Data analysis, according to Creswell (2009, p. 183), is a major part of a research where researchers present their findings in a way that brings deeper understanding of the information gathered, extract meanings and draw interpretations that will be offered to readers. He also stated that analyzing qualitative data is a continuous process beginning from the time of data collection and involves different steps (Creswell, 2009, p.184).

In conducting this study, I had used audio recording to collect data from all participants in focus group discussion, in-depth and key informant interviews were used except in one interview with a key informant. Prior to conducting the interviews, I first labeled the audio tapes with numbers so that it would be less time consuming as well as not to reuse/delete already recorded audio tapes. After conducting all the interviews, I translated field notes I took from Amharic into English every day and mostly while at the hospital so that to make sure that all observed information are still well remembered. In addition, I transcribed all audio records into fifty six text formats originally to Amharic and later to English.

For interview that two languages (in focus group discussion and in-depth interviews) were used, I transcribe the Amharic translations which were verified by another person (different from the translator used) who is a native Oromifa and fluent Amharic speaker to check if the responses given by participants and translations were all in line and for validity purpose. Later, prior to translating the transcribed data to English, summary of main points were extracted from the transcribed data and member validation was conducted with selected individual participants from in-depth interview in order to clarify the gathered information. Member validation is a way by which validity of a qualitative data is ensured through checking accuracy of findings by involving participants to verify the information they have provided is correct through viewing the final report or certain descriptions of topics (Creswell, 2014, p. 201; Bloor & Wood, 2006, p. 170).

Once member validation was conducted and data was cleared in a manner where identified insufficient and ambiguous information where checked and were cleared, the gathered data was translated into English language that was used to write the findings. Then, I read the transcripts thoroughly until understanding of the main points was achieved. While reading the transcript, I used different colored highlighters and stickers to underline significant participant quotes that impressed me in a way that provided in-depth picture of the situation. Later, specific issues or terms/words and recurrent issues in the text were used to code the data which gave rise to forty seven codes.

The codes were then categorized into thirteen in order to sort out texts into various segments, leading to a manageable data. A category, in this study, includes associated codes explored depending on the similarity and relationship under different headings. Later, themes of four were developed derived from the categories by extracting common and significant linkages. The final report was written after exhaustively examining the themes. To maintain anonymity and maintain confidentiality of participants, pseudo names were given to each participant.

3.5. Quality Assurance of the Study

Ensuring the quality of the data in qualitative research is important as the findings cannot be accurately measured and add up and are usually articulated in words rather than statistical figures (Williman, 2011, p. 72). Assuring quality of a study can be achieved through ensuring validity, a way by which the precision of the data is checked from the perspectives of the researcher, participants or readers (Bloor & Wood, 2006, p. 147; Creswell & Miller, 2000 as cited in Creswell, 2009, p. 191), of the study which can be conducted through employing different approaches.

One of the methods of ensuring the assuring the quality of the data is through utilization of member validation, a way by which validity of the data is ensured through checking accuracy of findings by involving participants to verify the information they have provided through viewing the final report or certain descriptions of topics (Creswell, 2014, p. 201; Bloor & Wood, 2006, p. 170). Therefore, this study had tried to ensure validity of the research through utilization of validation. Thus once the data was transcribed, follow up interview was conducted with selected participants so that they were able to verify the accuracy of the information they had provided.

Other issues to consider in assuring the quality of the study, according to Krueger and Neuman (2006), is ensuring objectivity and integrity of the research as there are "opportunities for biased, dishonest or unethical research" (p. 138). In qualitative study, according to Krueger and Neuman (2006), objectivity is ensured through stressing "human factor and intimate firsthand knowledge of the research setting" which implies that researchers should not detach themselves from events and people they are studying, to the contrary they should gain "personal insight, feelings, and human perspectives to understand social life better" (p.138). For that reason, I was involved in collecting all the necessary data through out. However, I had not used my personal values to judge the obtained information but rather I had tried to show my genuine interest in the participants' insight and encourage them to provide as much information as possible.

In regards to integrity, qualitative research upholds greater trust in the personal integrity of individual researchers (Krueger & Neuman, 2006, p. 138). In that note, this research had given due emphasis to the issue of integrity by being mindful of personal beliefs and biases that may interfere in obtaining unbiased information for the qualitative data and will also reflect the evidence gathered.

3.6. Ethical Consideration

Ethics in research is an important aspect and comprises different aspects of the research. Researchers must uphold and conduct their research with high moral and professional obligation (Krueger & Neuman, 2006, p.98). Researcher must be carried out with high regard to honesty and integrity in collecting data, presenting the findings and in citing others' work (Williman, 2011, p. 42). Krueger and Neuman (2006, p.98) assert that researchers must attempt to maximize the quality of information they produce while trying as much as possible to minimize risk to participants, colleagues, and society in general. In conducting research that involves humans as participants, according Williman (2011, p. 42) "always raises ethical issues" in our treatment which "should be with respect before, during and even after the research".

To Williman (2011, p. 43), there are two ethical issues that researchers must consider in research: the first is "the individual values of the researcher relating to honesty and frankness and personal integrity. And the second is the researcher's treatment of other people involved in the research, relating to informed consent, confidentiality, anonymity and courtesy".

Therefore, ethical consideration is an important and integral part of this study. In conducting the study, I had first contacted the Medical Director of the hospital and explained about the research. The Medical Director then referred me to Pediatrics Department where I had submitted the proposal in three hard copies along with letter from the School of Social Work and with my application for permission to conduct the research. I had first acquired permission from Pediatrics Department of TASH.

In addition to that, this study had put due emphasis to respecting the autonomy of each participant by acknowledging their personal choice to participate in the study which was effected through using informed consent (see annexes 1 & 5) which had assist participants to voluntarily confirm their willingness to participate in the study and be informed of all aspects of the study. The informed consent had included the purpose of the study, sponsoring institution, level and type of participant involvement, benefits and potential risks of participation, ways of maintaining confidentiality of the study and assurance of participants' freedom to withdraw from the study any time. Another aspect of ethical consideration is protecting privacy of the participants and maintaining confidentiality of information. In order to protect the privacy of participants, the study had not used any identifying information of the participants and had kept the communication of the result anonymous. Moreover, the findings of data are only shared with concerned professionals and only for professional purpose. However, the National Social Workers Association (NSWA) code of ethics state that confidentiality is breached "when disclosure is necessary to prevent serious, foreseeable, and imminent harm to a client or other identifiable person or when laws or regulations require disclosure without a client's consent". Accordingly, this study will breach confidentiality when circumstances raised above are visible following appropriate procedures and had included this information in the informed consent and will violate the privacy of the information if there is life threatening risk for the participant and/or other individuals.

The study had given due emphasis in using citations and avoiding plagiarism and falsification of information. In addition, during collection of data and writing the research report, the study had given emphasis to ensuring authenticity of all the findings and had not modify obtained information. Furthermore, I was very careful and strict not to use words that stereotype the participants based on their age, sex, ethnic group and disability. With regards to incentives/benefits, Kumar (2011, p. 245) states that providing incentives to study participants is not unethical when the incentive is given after the data is collected but it is considered unethical if incentives are given prior to gathering the data. Therefore, all parent participants were provided with fifty birr equally at the end of the data collection for dedicating their time in providing the necessary information. Participants were not informed at the beginning of the interview that there would be fifty birr incentive for participating and were provided at the end of the data collection procedure.

CHAPTER FOUR: DATA PRESENTATION

This chapter of the paper presents the findings of the study. It has six main sections comprising socio-demographic data of all participants, physical set up the pediatrics hematology/oncology unit ward identified psychological, social, physical impacts of childhood cancer on parents and coping mechanism of parents.

4.1. Socio-Demographic Data of Participants

This section of the paper presents the socio-demographic information of all participants in in-depth interview, focus group discussion and key informants. On top of that, description on children of participants has been incorporated as well. Pseudo names have been given to all participants.

Table1:- Socio-Demographic Information of Participants

Participant pseudonym	**Age**	**Sex**	**Marital status**	**Religion**	**Area of residence**	**Education Level**	**Occupation**	**Main income**
Kebede	35	M	Married	Orthodox	Wollo	9th grade	Farmer	Farming
Mekdes	35	F	Married	Orthodox	Addis Ababa	Tertiary education	Finance and Administration Manger	Salary
Mustefa	30	M	Married	Muslim	Butagera	3rd grade	Farmer	Farming
Askale	30	F	Married	Orthodox	Zeway	6th grade	House wife	Trade
Maritu	40	F	Married	Orthodox	Harar	8th grade	House wife	Farming
Woinshet	32	F	Married	Protestant	Feche	12th grade	Farmer (animal husbandry)	Salary
Senait	45	F	Married	Orthodox	Addis Ababa	12th grade	House wife	Trade
Ali	48	M	Married	Muslim	Arsi	3rd grade	Farmer	Farming

Table 2, illustrates the socio-demographic information of children who were diagnosed with cancer. As can be seen on the table, parent participant's pseudonym corresponds with child's information.

Table 2:- Socio-Demographic Information of children diagnosed with cancer

Participant pseudonym	**No. of Children**	**Information on cancer diagnosed child**				
		Child's age (years)	**Sex**	**Education Level**	**Type of cancer**	**Diagnosis time (in weeks/ months/ years)**
Kebede	2	7	F	Has not started	Willm's tumor	3 years
Mekdes	2	13	M	8th grade	Osteosarcoma (bone cancer)	2 months
Mustefa	4	11	F	2nd grade	Leukemia (blood cancer)	3 months
Askale	4	2 years & 10 months	F	Has not started	Leukemia (blood cancer)	3 months & 18 days
Maritu	4	12	F	8th grade	Leukemia (blood cancer)	1 months & 15 days
Woinshet	2	8	F	2nd grade	Leukemia (blood cancer)	2 weeks
Senait	-	3 years & 4 months	M	Has not started	Lymphoma	7 months
Ali	9	8	M	2nd grade	Leukemia (blood cancer)	2 months & 24 days

Table 3 presents the socio-demographic data of focus group participants. In this study eight parents had participated in the discussion.

Table3:- Socio-Demographic Information of Focus group Participants

Participant pseudonym	**Age**	**Sex**	**Marital status**	**Religion**	**Area of residence**	**Education Level**	**Occupation**	**Main income**
Abebe	45	M	Married	Orthodox	Welga	12th grade	Farmer	Farming
Alebachew	36	M	Married	Orthodox	Arbaminch	Unable to read & write	Weaver	Weaving
Zelalem	53	M	Married	Protestant	Ambo	3rd grade	Farmer	Farming
Gurmu	50	M	Married	Orthodox	Ambo	3rd grade	Farmer	Farming
Gemechu	28	M	Married	Protestant	Ambo	3rd grade	Farmer	Farming
Belay	30	M	Married	Protestant	Welga	12th grade	Farmer	Farming
Melaku	49	M	Married	Orthodox	Welga	Literacy & numeracy lesson	Farmer	Farming
Muhidin	65	M	Married	Muslim	Wollo	Literacy & numeracy lesson	Farmer	Farming

Table 4 illustrates the socio-demographic information of children of focus group participants. As can be seen on the table, parent participant's pseudonym corresponds with child's information.

Table 4:- Socio-Demographic Information of children diagnosed with cancer (participants of focus group discussion)

Participant No.	No. of Children	Information on cancer diagnosed child				
		Child's age (years)	Sex	Education Level	Type of cancer	Diagnosis time (in weeks/ months/ years)
Abebe	6	8 years	F	Has not started	Osteosarcoma (bone cancer)	3 years
Alebachew	3	8 years	F	Kindergarten	Leukemia (blood cancer)	3 years
Zelalem	9	7 years	M	Has not started	Leukemia (blood cancer)	3 years
Gurmu	9	4 years & 5 months	F	Has not started	Leukemia (blood cancer)	6 months
Gemechu	3	8 years	F	Has not started	Leukemia (blood cancer)	4 months
Belay	4	9 years	M	1st grade	Leukemia (blood cancer)	1 month & 2 weeks
Melaku	9	7 years	F	Has not started	Leukemia (blood cancer)	2 months
Muhidin	10	13 years	M	4th grade	Leukemia (blood cancer)	2 months

Table 5 shows the socio-demographic information of key informants. The key informants in this study were health care professionals engaged in provision of care and support to children with cancer at Tikur Anbessa Specialized and Teaching Referral Hospital. Alike parent participant's, the key informants have also been give pseudonyms as well.

Table5:- Socio-Demographic Information of Key Informants

Participant Pseudonym	**Age**	**Sex**	**Marital status**	**Education Level**	**Profession**	**Position in Pediatrics Hematology/ oncology unit**	**Work experience**	**Experience in Pediatrics Hematology/ oncology**
Michael	47	M	Married	Tertiary education	Physician	Head	23 years	9 years
Martha	45	F	Married	Tertiary education	Nurse	Head Nurse	25 years	20 years
Selam	28	F	Single	Tertiary education	Nurse	Staff Nurse	5 years	5 years

4.2. Physical Set Up of Pediatrics Hematology/Oncology Ward

This section presents findings gathered from key informant interview as well as observation made. Acquainting readers to the unit set up is believed to provide Pediatrics Hematology/Oncology ward is located on the sevenths floor of Tikur Anbessa Specialized Hospital, commonly known as D7 indicating the floor number and the wing. In describing the establishment of the unit, Michael, key informant, said

> A dedicated oncology ward was established on April 2013. However, pediatric oncology treatment had been given at the hospital for more than two decades. The hospital is the only cancer treatment center in Ethiopia for adults and children. And in case of children, it is the only diagnostic and therapeutic center in the country. In regards to pediatrics cancer, the expectation is of the total population under the age of fifteen years, 44% to be cancer patients and of which 10% to visit our hospital. What we expect is that 500 to 600 new diagnosis of cancer in children each year.

In regards to the environment of the ward, the first thing I have found in reaching the ward is the waiting area that has sofas and chairs. In explaining the purpose, Selam said

> The waiting area serves different purposes; first, visitors coming can stay there and enter patient room one by one. We have to minimize exposing the children to lots of infections so we have to minimize number of people entering our ward. Secondly, it serves as an entertainment area for children's play as well as during holidays where we have many visitors.

The second thing I had noticed entering the ward, unlike the other adjacent two pediatrics wards (B7 and C7), is the light green and blue wall paints with different animal and other paints that made me excited and sense that children may enjoy the paintings. I had noticed the paintings and the light colors throughout the ward and patient's room as well. Unlike other wards, there was sign that stated pediatrics hematology/oncology, which shows the type of ward it is.

The ward had twenty five rooms, fifteen of which are patient rooms while the remaining ten are different rooms (procedure, medication preparation room, kitchen, laundry, conference, nurse's office, counseling room, and others) that are necessary for the medical provision service. All the rooms are given room numbers and are also labeled in English according to their purpose. The maximum number one patient room can accommodate is two bringing the total patient number the ward can admit to twenty six. All patient rooms have their own bathrooms and very clean.

I was very much impressed by the play room that was available for children in the ward. The room was filled with different books, toys and puzzles. Martha said

As part of treatment for children with cancer, play therapy helps the children psychologically. The room is only available for children who are admitted or out patients but they need to be cancer patients as other children are not allowed to enter. The play therapy is facilitated by a volunteer psychologist.

As for number of staff, Martha said, "the unit has fourteen staff nurses and one senior physician currently on fellowship program me on pediatric oncology. Apart from that, there are residents and interns that practice in the ward for a month at a time".

The unit provides service for both in patient and out patients children diagnosed cancer. According to Michael having a dedicated ward with staff nurses is important to the service delivery and treatment that is provided for children with cancer. The ward provides medical support to children with cancer at an inpatient and outpatient levels.

According to Michael, children are admitted for different reasons falling into three major categories. He said

> When biopsy is needed to diagnose and surgeons could not perform the procedure over local anesthesia, which is very common in children, we admit the children and biopsy is taken under general anesthesia. Another reason for admitting children is for therapeutic purposes especially when the treatment children are going to take is intensive in case of Leukemia patients for instance where when we need to follow the children closely, monitoring their laboratory results.
>
> And also when the treatment they will need to take requires for them to take be hydrated which is 48 to 72 hours prior to administering chemo medications is also another therapeutic criteria for admission. The third criteria for admission is when we need to provide supportive treatment for instance when children develop

hypertension or other related issues, we admit them and provide them treatments and follow them closely.

4.3. Psychological Impacts of Childhood Cancer on Parents

The psychological impacts and aggravating factors are discussed in this section of the chapter. The section is organized into two sub-sections that present parent's emotional reactions to the diagnosis of a child with cancer and the aggravating factors.

4.3.1. Emotional Reactions

This section presents the emotional reaction that participant parents had experienced. Emotional reactions of shock, fear, worry, sadness, stress, hopelessness, guilt, numbness, disbelief and difficulty of accepting had been experienced by participants in relation to child's diagnosis and illness with cancer. The findings of the study show that participants had experienced more than one emotional reaction not only when hearing the diagnosis of their child but also across the process of child's treatment

Shock

Shock was one of the reactions parent's had when they were informed of child's diagnosis with cancer which was found to be a common reaction among participants in both categories. However, Senait, had said that she was not shocked when she heard her child's diagnosis from a physician. She said

> I was not shocked when my son's diagnosis was confirmed because he was admitted here and was already taking chemotherapy medications. The doctors were waiting for the biopsy result to confirm but they had also started the medication to prevent the mass from growing. On top of that, all the children that we were seeing in the ward were all cancer patients and in worse conditions than

our son, and that made me and my husband to expect that it could be cancer and we were prepared for that.

Parents who had awareness about cancer experienced shock when hearing their child's diagnosis the first time than parent's who had no awareness about the disease. However, parents who had no awareness about the disease, experienced shock from what health care professionals and other people had said. Ali said "I have never heard about cancer when I was in Arusi. I was shocked when the doctor in Adama told me that my son had a very difficult disease called cancer. And that I must to take him to Tikur Anbessa".

Fear and Worry

Other emotional reactions study participants had experienced were fear and worry as a result of their child's illness with cancer. Fear among parents of children with cancer, arise due to different factors. The thought of their child's death, if parents had previous encounter with person diagnosed with cancer and had seen pain and suffering as a result, which also make parent develop fear. Mekedes, mother of a thirteen year old boy explained why she fears as "I worry and fear every single day. I fear every word that comes out of my son's mouth. The other day he asked me 'does this mean I will not be able to run anymore'?" Similarly Ali had said "the more I heard about cancer, the more I started to fear that my son would die". Woinshet had said that she had always been "terrified of cancer" which aroused due to seeing a close relative suffer immensely from a cancerous tumor and the experience frightens her now that her daughter has cancer.

In this study, I had found worry to be a common experience among participants. Several factors associated with child's illness with cancer had made participant parent's to be worried. Child's survival and resuming better health, cost of medications and diagnostic procedures that were not available at hospital, in-availability of medicines even in private pharmacies, conditions of their children and spouses left at home, and making the right medical care decisions on behalf of sick a child were identified as factors that worry participant parents.

The most prominent factor for worry among FGD participant was associated with cost of medications and diagnostic procedures that were not available at hospital and the conditions of their children and spouses who were left at home. As explained by participant, the two factors prominent among FGD participants were found to be related.

Stress

Another emotional reaction that was experienced by participants was stress. Child's health condition, re-occurrence of disease, un-availability of medicines, financial problems, and not knowing survival of child were identified as factors that made participants to feel stressed. To elaborate more, Mekdes expressed the situation as "there is lack of chemo medicines and are very difficult to find. It is also very expensive to buy especially in pharmacies outside the hospital. When the medicine is not available at all, it is very stressful".

Hopelessness

Moreover, study participants had experienced loss of hope in the process of their respective child's cancer diagnosis and treatment. Hearing child's diagnosis first time (among parents who had awareness about cancer), re-occurrence of the disease, child developing infections, when given long appointment dates for treatment in supplementary units, and financial problems were among the reasons that had made participant parents feel hopeless. In contrast to identified factors, Mekdes said "there are many situation where you would lose hope, for me, especially the questions my son would ask make me think that he may never get better and I … (pause, sad look on her face) lose hope then".

In addition to that, there were situations that had made parent participant's to lose hope in the focus group discussion. In explaining one of the situations that made him lose hope, Zelalem, FGD participant, had said "my child has been following treatment for the past three years. When I heard rumors that cancer killed Meles Zenawi, I lost all hope (waiving his hand in frustration)". On another parent's case, it was a remark given by another parent that made Mustefa feels hopeless. He said "she said that children with blood cancer do not survive and she herself is a mother of child with tumor that. I felt hopeless".

Sadness and Crying

Sadness and crying were also other emotional reactions identified by study participants as a result of their respective children's health situation which was experienced on different occasions throughout the process. In regards to crying, elaborating further, Mekdes had said "I cry every time I set foot in this ward. I start crying the minute I reach the ward door (pointing towards the door). I cry when I see children dying, I put my son in that position and I cry". Likewise, Selam (key informant) had stated that parents of children with cancer, and especially mothers, cry more frequently. During the period of data collection, I was able to observe three mothers of children with cancer who were talking about their respective children's cases and crying in the waiting area of the ward (Observation, May 13, 2014).

Guilt

Another emotional reaction to diagnosis of a child with cancer identified by participants was guilt. In that regard, Mekdes said

> When I first found out my son had cancer, I felt guilty. I asked myself, as a parent, what my mistake was. Should I had taken him to the doctor's right after he had been hit the first time at school playing with his friends or was there some mistake I had made when I was raising him.

Similarly, Maritu said

> I feel that my daughter would not be sick if she had not had so many responsibilities at home. She is a type of child who would sort things out and make plans before I even ask. I ask myself if it is my stress and worries that made her sick.

In contrast to both mothers, Askale explained that she never had guilty feeling, "I made sure my daughter had everything and had provided her care and made sure she had clean food. It is God's work and I cannot fight with him".

Disbelief and difficulty of accepting

Disbelief and difficulty of accepting of child's health condition were also other emotional reactions identified by study participants as a result of childhood cancer. In regards to disbelief, Woinshet expressed her experience as

> I had five test results on my hand and all but one say normal. I asked the nurse what it said and she looked at it and said it shows blood cancer. I was shocked (frowning her face) I could not believe it.

Mekdes expressed why it is difficult for her to accept and throughout the interview she had mentioned the word "it is hard to accept" five times.

> I cannot express what I felt when I first heard that my son had cancer. It is so hard, as a mother, especially one who had sacrificed a lot ... giving birth to both my children at an early age. I withdrew from school and quit my work to raise them myself (fighting her tears). It is hard for me to accept this. You hear that packed and processed foods bring cancer. But I never fed my son such kinds of foods. I made sure his foods were clean and I made sure he took his vaccination on time. I raised him with the at most care (shaking her head and fighting tears) it is hard to accept.

Numbness

Feeling of numbness was identified by one mother as her reaction when she heard her child's diagnosis with cancer. Mother of two years and ten months old child diagnosed with blood cancer, Askale said "when I first heard that my daughter had blood cancer, I felt numb (frowning her face)... my mind and body were both numb (holding her head with both her hands)... I do not remember what happened after that".

4.3.2. Aggravating Factors

Participant parent's reactions to child's diagnosis with cancer were aggravated by different situations and vary from one parent to another. The finding of this study show that parent's awareness to the disease, their perception, the way information was communicated, health condition of child, remarks of other people including family members and issues related to medical care had been identified in this study as aggravating factors of psychological impact of childhood cancer on parents.

4.3.2.1. Parent Participant's Awareness and Perception of Cancer

This section of the study finding presents parent's awareness of cancer prior to their child's diagnosis and their perception. Understanding study participant's awareness of cancer prior to child's diagnosis with cancer and their perception is imperative as it enables to look into how parents react to the situation and adjust themselves to life changes that had come about.

Parent participant's awareness of cancer prior to their child's diagnosis varies across participants. There were participants in-depth interview who had never heard about cancer in their area of residence at all prior to their child's diagnosis. In reinforcing this, Ali said "I have never heard about cancer where I am from which is Arusi. I have not even told my wife what our child has. I just told her that he has *'tenecha'* (some form of tumor)".

In contrast to that, there were other participants who had some form of awareness about cancer in general and specifically about adult cancer. However, Maritu had awareness about cancer in children. She said

> I saw Mathiwos' father on television talking about cancer in children and I always wanted to know more about it, how it occur especially on children, how long it would take to recover, what accidents bring it, how it passes from people… though I had never seen anyone who was sick where I live.

The findings of the study indicate that parents who had some form of awareness about cancer had experienced reactions when they were first informed. However, it is not to mean that parents who had no awareness had not experienced reactions, rather their reactions were related to other factors such as what they had been informed about the disease from others including health care professionals. Similarly, the experience of FGD participants was also similar with in-depth interview participants where some participant's had awareness about caner in adults while others had never heard about it. Melaku, FGD participant, in sharing what he had heard, "what I have heard about cancer is that if it is breast cancer then the breast has to be removed, if it on the leg then the leg has to be removed for people to recover…" (with a questioning look on his face).

In regards perception about the disease, Kebede had expressed it as *"beshatew rasu seaitan new"* (the disease itself is the devil). Whereas other participants had perceived it as a disease that would cause death and associated their child being diagnosed with cancer as they had been told their child had died and in some instances when parents lack the financial capacity to buy medicines, parents assume that their child would die. Similarly, FGD participants had also perceived cancer with death and associated parent's lack of financial capacity to buy medicines with child's death. However, cancer was also perceived as a disease that "destroys property, weakness the sick child and will not leave the child" by Alebachew.

4.3.2.2. Sudden Onset of the Illness

Another aggravating factor which was identified in this study was the sudden onset of child's illness which had resulted in parent's coming to Tikur Anbessa Specialized Hospital without any preparation. According to the findings of the study, fourteen participants reside outside of Addis Ababa and had traveled long distances to receive medical support to their respective children. Most parents had stated that they were not prepared financially or in settling issues related to their livelihood. In respective to that, Kebede said

> I took her to Dessie health center and they referred me to Tikur Anbessa. We came here and she was admitted and had started chemo and then she had surgery to remove the tumor and we had stayed here for nine month. I had never expected we would stay that long. This time around, we came here for her check up and I was told that the tumor had re-occurred and that she needs to stay here and take medications and have surgery again. I only brought 1,600 birr with me and I have already spent 1,500 birr on CT scan.

4.3.2.3. Communication

In regards to impacts childhood cancer on parents, the findings of this study indicate that the situation in which parents had been informed of their child's diagnosis from health care professionals and what family members and others comment aggravates psychological impacts.

In regards to communicating information to study participants from health care providers, the study had identified that it had brought impact on some parents. According to Woinshet

> We (her husband, her daughter and herself) were at the emergency room and my daughter had taken blood the day before. I had five test results on my hand and all but one say normal. I asked the nurse what it said and she looked at it and said 'it shows that you daughter has blood cancer'. I was shocked (frowning her face) I could not believe it. A day before they had said that it shows a lump on her liver and spleen. Then I asked her how is it? and her response was 'she may live or not'. I started to have headache, I hated seeing people, and I even hang up my phone on people and cry even while standing there.

Similarly, Mustefa had stated that "I had asked a physician I had found passing by to look at a test result and he told me there that it says that my daughter has blood cancer. I was shocked". Similarly, Mekdes had said

> The situation in which I heard my son's diagnosis was very difficult. I heard it at the private hospital I first took him. The physician at the time laid everything on me. His approach was very dangerous (nodding her head sideways in disapproval). If I had some other health problem I may not have lived, I may not have cared for my son.

In contrast to their first experience, both Mekdes and Mustefa had stated that they later had been reassured by other physicians. As much as communication is important from health care providers, communication from family members and other people also had impact on parents. In relation to that Kebede had said

> I had no idea about cancer when I first came and heard about if from other parents in the hospital. I asked them 'what is this cancer? Do doctors cure it?' and one parent said that it had killed all the children. That shocked and scared me.

However, for FGD, in addition to what they had been told from health care professionals, it was what close family members would say had been presented as aggravating the psychological impacts. In that note, Gemechu had said "I am stressing because my relatives are saying that I will spend the remainder of my money for a coffin and burry my daughter as she will not survive".

4.1.1.1. Issues Associated with Child's Medical Care

This study had identified factors associated with medical care of child aggravated psychological impact on participant parents in this study. The identified factors were related to medication expense, in availability of chemotherapeutic medicines and cost of diagnostic procedures. Study participants had stated they had experienced psychological impacts manifested through emotional reactions stated above as a result of the three factors identified in the study. The three factors mentioned here are discussed in more detail in the social impact section of the finding.

4.4. Social Impact of Childhood Cancer on Parents

The findings of this study also identified social impact of childhood cancer on participant parents. The main identified social impacts are changes in social activity, changes in family role and responsibility, changes in marital relationship and economical problems. The sub-themes are discussed below in more detail.

4.4.1. Impacts on Social Roles

This section presents the impacts brought by childhood cancer on family and social roles and responsibilities parent participants.

4.4.1.1. Family Roles and Responsibilities

In respect to changes in their family roles, the major impact identified by study participants was inability to provide for family. Thirteen parent participants used to be breadwinners for their families while one participant shared the responsibility with her spouse. Most of the study participants (thirteen) were engaged in farming and as a result of their respective children's illness their families had faced grave challenges.

All FGD participants had the role of provider for their families. However, due to child's illness they had now assumed the role care provider for their respective sick child, while no one had filled in the role of provider they used to fill. As a result of that, participants had stated that they not harvested their crops and had not cultivated their land, leading to inability to provide food for their families.

In relation to addition of responsibilities, Mekdes had expressed that caring for a child with cancer had added burden on her responsibilities as a mother to a sick child and another healthy, wife and care provider for her child.

4.4.1.2. Social and Community Roles

As for impact in their societal and community roles, all study participants had indicated that the social roles that they used to perform in their area of residence, such as visiting sick people, attending social events such as weddings, funeral, christening and others had been affected. Fourteen study participants had indicated that as they had traveled far from their home to follow medical treatment for their children they were not able to maintain the social activities they used to perform. However, Mekdes who is from Addis Ababa, the case is different. "I do not have social life anymore; I do not know who is giving birth, I do not attend funerals or visit anyone. My son needs care full time and because of that I had completely isolated myself".

4.4.2. Impacts on Marital Relationship

The findings of the study indicate that child's diagnosis with cancer had impacted some participant's marital relationship while others had stated that it did not. Kebede had claimed that his wife used to mistrust him as he had spent nine months in Addis Ababa following up treatment for their daughter and had not disclosed their child's actual diagnosis to her. For Mekdes, her son's illness had impacted the communication with her husband. She said "it had changed our communication. Now all we want and talk about, read about and hear about is our son's case. We had stopped talking about anything else".

However, argument with spouse was prominent among FGD participants due to financial problems they had encountered as a result of their child's medical treatment. In that regard, Melaku said

> The argument with my wife was over the phone about financial issues. What she said was 'you are telling us to sell the remaining property and send you money. What am I going to sell and send you? Where did you take all that money you took? At least the government is feeding you and the child 'enjera'. What am I going to feed the once here?' That is what we argue about.

In contrast to that, in case of Woinshet who took a position that her priority is her daughter rather than her marriage and said "I am not in a position to think about my marriage. You cannot think about marriage being in separate places".

Both Martha and Selam (key informants) share that cancer in children affects parent's marital relationship. According to Martha, who had twenty years of experience in pediatrics department of TASH,

> In my experience, I have seen a father leaving his wife because their child was diagnosed with cancer. We had a father, when we were in B7, who was caring for his daughter with cancer and his wife was at home with their second child. While he was here, his wife left their child with their neighbors, sold all of their belongings and left for one of the Arab countries. He cries whenever he comes here.

In contrast to the above findings, there were participants who had claimed that they had not encountered marital problems rather they discuss with their significant others and they support each other.

4.4.3. Economical Impact of Childhood Cancer on Parents

The study had found out that childhood cancer had brought economical impact on participants associated with disruption of work, expensive cost of chemotherapeutic medicines and diagnostic investigations.

4.4.3.1. Disruption of work

The fact that their children had been diagnosed with cancer and following treatment for a long period of time, parents work had been disrupted which had exacerbated their financial problems. Mekedes said

> The minute I heard my son's diagnosis, I called my office and told them his diagnosis and never went back. Now I am on my third month. My boss suggested that I took leave without pay and I recently went to facilitate that. Even if I did go back to work, I do not think I will be able to work and I do not think I will handle my responsibilities. Financially it is challenging as my husband is the only one working and it is hard to live on a single person's salary but our son needs care full time.

Similarly, participants had indicated that their works had been disrupted. Where the main income of the family was farming, participants had indicated that following medical treatment for their respective children and staying in Addis Ababa for months at a time, it was impossible for them to cultivate and harvest. This disruption of their work, according to the participants, had significantly affected their families.

For other participants, although their spouses were the bread winners and were still working, their respective children's illness had impacted their spouses work as they travel back and forth between Addis Ababa and their area of residence or to the hospital two or three times a day. Moreover, Selam asserted that work disruption was very common in parents with children with cancer.

> For instance in case of Leukemia patients, usually it would starts as fever or bleeding and parents would take their children to health facilities. Then they are told they need to take their child to Tikur Anbessa urgently. And here (in the hospital) they end up staying three and four months without being prepared for anything.

4.4.3.2. Cost of Medications and Investigation

In regards to cost of medications and investigation, participants had stated that medicines that were available in the hospital were given to free patients (known as 'nesa takami' ነፃ ታካሚ in Amharic) and available at the pharmacy inside the hospital (known as 'leyu' pharmacy in Amharic) for paying patients. However, when medications were not available in the hospital, parents were forced to procure from private pharmacies. The challenge parents stated in this regard is that the medications were only found in specific number of pharmacies and were very expensive.

Costs of medications were voiced prominently among FGD participants as the main impact participants had encountered. In further explaining how expensive the medications were, Belay said "I bought three vials of chemo medication for 3,000 birr from a pharmacy in 'Kera'. The total number of vials he needs to take is nine and now I am left to buy the remaining six vials".

Similarly, for diagnostic investigations that were not available in the hospital, parents were forced to incur cost at private laboratories which again were very expensive. In that regard, Woinshet said,

> Financially it is damaging. For instance we had spent 700 birr for blood investigation. And then we had bought different medications … imagine she had not even started the main chemo medications yet … and so far, in two weeks, we had spent about 3,000 birr.

FGD participants had discussed the different costs they had incurred for their respective children's medications as well as diagnostic investigations had brought financial impact

Selam shared the notion that parent's encounter financial challenges as a result of cost of medications and diagnostic investigations voiced by participants. She said

> Parents are really challenged financially. The main chemo medications such as Asparginase, Bleomycine, Actinomycine B and Cytarabine are very expensive and were not available in our hospital. Which means everyone, both free and paying patients, would need to by them from pharmacies outside. Even if there are organizations that were willing to cover the cost families incur for the medications, the challenge is that the pharmacies do not provide receipts. As for investigations, our laboratories do not usually conduct liver and renal function tests, which mean parents, have to go to outside laboratories to have them done and are also expensive.

FGD participants had stated that the economical impact associated with child's illness had resulted in affecting their family through disrupting their children's education, unable to afford travel expense to go home in case of Zelalem and unable to afford accommodation as a result forced to sleep under hospital benches in case of Abebe. In sharing the experience of other families had encountered, participants had stated that as a result of huge economic impacts on families, in some instances parents were unable to take home their deceased children's corps to their home for burial. In that regard, Gurmu said

> There was a man who came from 'Wolega' and his daughter passed away and he did not have money to take the corps. So we collected around 1,600 birr here and we bought one coffin for 600 birr. Then we have found a car that could take them but the driver asked us 5,000 birr. Imagine 5,000 birr to take a corps. We did not have any choice so we paid the 1,000 birr that was left as advance and sent him home.

4.5. Physical Impact of Childhood Cancer on Parents

Study participants had experienced different physical impacts as a result of their child diagnosis with cancer. In addition to that, two parents had stated that their respective child's diagnosis with cancer had exacerbated previous and existing health conditions.

Study participants had stated that they had experienced tiredness and lack of energy ever since their respective children's illness. According to the study participants, the physical impacts are related to lack of sleep/disturbance which all participants in in-depth interview had revealed that they had problem with sleeping especially when their children were sick. According to Mekdes, "the fact that you are sleeping here, on the floor has its own impact ...I sleep worrying... and the whole day I feel tired". Similarly, Woinshet said "I doze off rather than sleep... I wake up when she moves her hand or hear her grant. And I spend the next day tired, not having the energy even to think". Likewise, other participants had stated that they had experienced feelings of tiredness and loss of energy. However, some parents had stated that through time, their sleeping patter had gotten better though it is difficult to have a "peaceful sleep" in the case of Mustefa, Askale and Senait.

Other identified problems were associated with lack of appetite and in some cases weight loss in the case of Maritu. In elaborating, Senait said

> You lose your appetite not only because of your child's health problem but also because of what you see here (looking around and frowning her face) ... when you are trying to eat your child gets sick or you hear someone yelling and crying because their child had died ... all that make you lose your appetite".

Another factor identified in this study was that child's diagnosis with cancer had exacerbated two participant's previous health conditions. Maritu, a mother of four children from Harar, was a known diabetic patient on medication. She said

> I was in Hara when my husband called and told me that our daughter has blood cancer. My sugar shoot up ... I had feelings that it has increased so I went to the hospital. They tested me and the doctor told me that I need to be admitted, I refused, I told him that I do not have the time or the desire to stay as I am going to Tikur Anbessa. I asked him to just give me something that will reduce it. We argued for a while and I told him the situation I was in. He finally agreed and gave me the medication but warned me to seek help immediately I reached Addis. I did as he told me and now... the doctors in Addis have put me on insulin

injection as the tables cannot control it any more. It still fluctuates when I get a little bit angry or sad (fighting her tears and gazing through the window).

Similarly, Ali, previously a soldier, had bullet injury on his right upper thigh. (Rolled up his trouser to show me the scar) when I brought my son from Adama, I do not remember what happened but my leg had swollen. I have always had problem on my right leg as a result of the bullet injury so I do not wear flip flops because they are not comfortable for my leg. But after my foot had swollen, the shoe I was wearing would not fit so I had to buy and wear flip flops (showing me his swollen foot).

4.6. Coping Mechanisms of Parents

Study participants utilized different methods to try to cope with the impacts of childhood cancer. Categorized in tow sub-sections, this section describes how parents cope with the situation as well as the different psychosocial supports that assist them in coping.

4.6.1. Parents Coping Mechanism

The findings of the study indicate that study participant's use different methods depending on the situation as a coping mechanism. One of the coping mechanisms that participants have stated was crying, more common among female study participants. Participants used crying as an outlet and solution for their problems and felt relieved afterwards.

Another coping mechanism used by study participants was relaying in their religion/faith. In accordance to that, participants had identified that praying and putting trust in God and Allah (according to their respective religions) had enabled them to cope. In this regard, Woinshet said

> My husband and I were together when we first heard her diagnosis and she was right next to us. From our reaction she knew it was something serious and she said to me 'there is God for me'. Right there, I said let her take the medication let what God wishes happen. I have now decided that there is God who cares more for her than me, he is the one who gave her to me and who has raised her. And this has come as a test for me.

Similarly, Mustefa said "I am Muslim and I pray every time so that Allah would give me strength and save my daughter".

Another coping mechanism only identified by parent Mekdes was, as she had referred it *"wed ras memelse"* (returning to self). Elaborating more what it means, she said

> I started to look into myself. I now know that my being alive is very important to my family and especially to my son. I am trying to make myself strong. I may not sleep eight hours like most people but at least now I am trying to sleep for four hours. I am planning on staring a part time job, thanks to God my field of study allows me to work part time, which will be good as it will support my family financially and at the same time I think it will distract me from my son's sickness.

Financial impact of childhood cancer had been voiced by study participants repeatedly. Participants had identified having free paper (referred as "ye nesa worket" in Amharic), selling their properties and contracting out their lands as coping mechanisms for the financial challenges they have encountered. Accordingly fourteen participants had brought free paper from their respective local administration and were registered by the hospital and their children were receiving services that were available in the hospital without paying.

In regards to selling proprieties, participants from both groups had stated they had sold their cattle and in some instances, their house as well. In discussing what he had to sell, Ali had said

> I had two oxen and I sold one when I came here for 6,000 birr. I had 5,000 birr when I came here. If I showed you what I have in my pocket (opening his shirt pocket to show me), you would cry.

Another financial coping mechanism that was used by participants was contracting out their farm lands as they are not there to farm the land which was used by FGD participant's as it enabled them to generate income rather than their land remaining idle.

4.6.2. Psychosocial Supports that Assist Parents to Cope

Study participants had identified different supports that had assisted them in coping with the situations they were in. Social supports, from different organizations, from the hospital, and health care works were identified as support systems that assisted parents to cope. Below, the findings under the different sub-themes are presented.

4.6.2.1. Social Supports

Supports from family members, 'idir', friends, neighbors and religious leaders were discussed by participants as supports that assisted them to cope. Support from family members, where family members took responsibility of looking after children at home and farming their lands had been stated as a huge supports among participants.

Whereas, for Senait, her domestic helper was mainly responsible in looking after the children while family members and neighbors help out whenever they.

'Idirs' were also identified as one support system. However, in regards to that, two contradictory notions were identified during in-depth interview. Kebede had stated that his 'idir' (also called 'kere' ቀሬ local term in Wollo) had been a huge support in the course of child's diagnosis with cancer and treatment. In contrast to that, Ali had said "there is no such thing as support from 'idir' where I live. If the father is there, he does what he can if not you leave it. If the owner is there, he can handle it if not there is nothing. It is not even the culture" However, FGD participants acknowledged the existence of social supports from 'idirs', but as farming consisted several and difficult continues processes, it would be difficult for members to farm other people's land.

Another social support identified by participants was from neighbors. Through their prayers and moral support, Woinshet had stated that her neighbors had helped her while Senait stated that, her neighbors even "stay over the night with my children at home when my son is sick and both me and my husband had to stay at the hospital". The other support participants had received was from religious leaders through their prayers. In contrast to that Ali had said that "there is no such type of support from religious leaders from where I came".

4.6.2.2. From health care professionals

Study participants had identified that health care professionals had roles in enabling them to cope with their children's diagnosis. Kebede had said

> Doctors had informed me about my child's health. I had been informed where the tumor is located and that it has not spread to her other parts. I had also been told

> that cancer and its treatment were very tough and that it was not something that would end in a short period rather that it will take a long time. This information had helped me a lot and is very important to parents. Because without knowing exactly, you spend all your money and when you child dies, it will be difficult to find money to take the corps back home.

Similarly, Mekdes had said that she had an opportunity to discuss with a senior physician of the unit for forty five minutes about her son's health issue which was very helpful for her. In addition to that, the same participant had said "the nurses here are very understanding, supportive and are willing to help not because it is their job but out of humanity". Similarly Senait also shares the participant's claim.

The counseling both the above mentioned participants had stated, according to Martha, is referred as "medical counseling which is primarily given by physicians and is mainly about the disease, medications and their side effects and related things". However, Selam said "even the medical counseling is not properly given. Sometimes parents are roughly told about the case. Sometimes during rounds, parents are told that their child will start medication. Sometimes they might be told about the case".

Both Martha and Selam assert that there was no proper psychological support in the ward for parents. Martha said "as nurses, although we do not have proper counseling training, we try to reassure parents as much as we can". Similarly, Selam said

> In my point of view, to begin with, there is no psychological support. There is no counseling where parents would come, taking time, in informing and discussing with them about their child's case kind of counseling. In addition to that, there is no one who would help them to address the social problems they are faced with.

4.6.2.3. Support from Organizations

Different organizations work with TASH hospital and specifically with pediatrics hematology/oncology unit to provide support for children living with cancer and their parents. The supports presented in this section are those that participants had identified and those key informants had described.

Mother Tressa Missionary shelter

Mother Tressa Missionary shelter located in 'Asko' (also referred as 'Asko' by parents) area Addis Ababa was identified by FGD participants as providing a huge assistance and support. In their own words 'hiwot achnen yaterfe' (what has saved our lives). In explaining the reasons, FGD participants had stated that the shelter provides them with a place to sleep for them and their children, provides them food three times a day and provides them with sanitary materials for them and their children.

Sharing their personal views, Gemechu said "for food and anything else, I was able to cope a little better after I had joined Asko. Before that, I was even thinking of leaving the girl on the streets and go back home". Similarly, Abebe said "if they did not write me a paper and had not joined Asko, I was thinking of either to hung or throw myself into a moving car and kill myself".

According to all key informants, Mother Tressa Missionary was one of the best social support organizations that provided fifty patients and their parents coming from regions who did not have sufficient or no family support in Addis Ababa. In addition to the services participants had mentioned, the organization also provided simple laboratory test (Complete Blood Count also called CBC) and facilitates transportation three times a week from the shelter to TASH and back for children and their parents while

International Network for Cancer Treatment and Research, USA (INCTR-USA) covers the cost of transportation.

Likewise, in discussing the importance of the shelter in the outcome of medical treatment of children, Michael had said

> We can say100% of all cases coming to our hospital are brought at an advanced stage which by itself had implication on the outcome of the treatment. On top of that patients default as parents, for several reasons, are economically drained. The support this shelter had enabled in reducing the defaulter rate and somehow minimized the economic challenges parents face.

Ye Mathiwos Wondu Ye Ethiopia Cancer Society

Another organization that was identified is Ye Mathiwos Wondu Ye Ethiopia Cancer Society. The organization has been providing support for families for years. In regards to the support the organization provides for families, Selam said

> The organization supports fifty parents who are economically challenged and most of whom from different regions of Ethiopia. The support includes covering any type of diagnostic procedures and medication costs. For the medications, as long as there is receipt, the organization covers but the challenge is finding receipts. Most of the patients of the organization are out patients but in some instances if the children are admitted, the organization gives them more than one hundred birr per week for food.

Another support parents had identified which occurs was during holiday periods. Different people would and spend the holiday with them, playing with the children. Selam had stated that organizations such as Ye Mathiwos Wondu Ye Ethiopia Cancer

Society and an association called 'Enem Le Wogne' celebrate holidays with the children and parents. She said,

> Ato Wondu with his supporters organizes lunch and traditional Ethiopian coffee ceremony for holidays. On top of that they also organize music and poem competitions for the children and give presents to those who win. Apart from that they also give out cakes for everyone (including staff) and provide every parent with 100 birr and soaps. They spend a very good day here.

International Network for Cancer Treatment and Research, USA (INCTR-USA)

Other support participants had identified that had been helping them was the traditional coffee ceremony organized twice a week on Tuesday and Thursday afternoons called *'Nu Buna Tetu'* (come and drink coffee). Organized by the head nurse of the unit, parent's gather and had coffee while discussing issues that were of their concern related to the service in the ward, the challenges they are facing in the medical service delivery of the unit, experience sharing with parents of cancer survivor children and those who have lost their children to cancer. Participants had stated that the discussions held during the coffee ceremony, had helped them tremendously. According to Mustefa, the experience sharing had given him hope.

According to Martha, the coffee ceremony was sponsored by INCTR-USA and the parents who came and share their experience were members of Tesfa Addis Parents Childhood Cancer Organization (TAPCCO), established by parents of cancer survivor children and health care professionals in the hospital. The parents of the organization, according to the same key informant, share their experience with parents in relation to what the care and support was like when their children were sick, about medications and other issues.

Another huge supporting organization identified by all key informants was International Network for Cancer Treatment and Research, USA (INCTR-USA). According to Michael, "INCTR-USA had signed Memorandum of Understanding (MoU) with FMOH and the hospital. They had renovated the pediatrics hematology/oncology unit. They had also provided us a fellowship program". Similarly, Martha said "INCTR provided us with protective materials such as gloves, aprons, masks for nurses as the medications have hazardous effects, vital sign materials such as thermometer, pulse oxymeter, blood pressure calf and other supports".

Enem Le Wogne Association

Another local supporting organization participants and key informants had identified was an association called 'Enem Le Wogne'. The major support the association had made was donation of twenty six mattresses. Selam had said "previously, parents used to sleep on cartons on the floor and now they are sleeping on the floor but on mattresses". Apart from the donation, the association had organized a lunch programme for children and the parents during Easter for the past two consecutive years.

Fekat Circus Group

Another support parents had identified that had assisted them is children's play time that took place twice a week on Monday and Thursday from 4 to 6 pm. According to Ali, "the program is also good for parents because seeing the children playing, does not make the disease disappear but takes away the thoughts". Similarly, Maritu had said

> The children's play brings me joy and happiness. I just get up and dance with my daughter (smiling … the first time I saw her smile). They assign the children into groups of cats and mouse, and the children play and they become very happy. As I have never thought I would see my daughter play again and seeing her playing and enjoying, makes me very happy. I forget the disease and the stress I was feeling, just disappears. Seeing the other children playing and enjoying also makes me really happy (smiling).

As for children's play program, Martha had explained that it was initiated as a play therapy for children and there were two types of programs. The first was the one organized by Fekat Circus Group commencing twice a week on Monday and Thursday. And the second one was available for the children inside play room of the ward facilitated by a volunteer psychologist. Martha said

> Fekat Circus Group organize play program for all the children in the hospital. But the program for our children is a separate one as the children are susceptible for infections; they cannot be mixed with other children. The group had understood the health challenges these children face and provide the service with utmost care.

In the wards waiting room, the ward cleaners would clean the floor and then members of the circus group first dust and clean the sofas, tables, benches and children's chairs with antibacterial solutions. Then they clean their hands with the same solution and provide everyone coming in to participate in the event anti-bacterial solutions to clean their hands. After the initial safety precautions, they put out books, paints any other materials on the tables and turn own children's music which sends the signal for all the children and parents in the ward that the program is about to start (observation May 13 and 15, 2014).

Volunteers

In addition to different organizations providing support, there are also volunteer individuals who provide assistance to parents at different times. In describing that, Martha had said,

> There were individuals who celebrate holidays or spend time on normal weekends and invite the children and parents lunch. There were also others who donate money for parents even Ethiopians who came for a vacation from abroad donate. In addition to that, also school students, for instance Cathedral students, who donated to children with cancer.

Tikur Anbessa Specialized Hospital

TASH as a health institution provides basic services of diagnostic and therapeutic services. Apart from that, the hospital also provided food for admitted patients. In case of pediatrics hematology/oncology patients, according to Selam,

> Free patients had access to receive available services in the hospital free of charge while paying patients pay for the services. What had improved in service delivery from past years is the nutritional support for cancer patients. Children are provided with protein diet such as eggs, beef, and one liter milk per day and depending on the need, gruel.

Accordingly, fourteen study participant's children were registered as free patient's and receive available medications and diagnostic procedures for free.

According to Michael the establishment of a dedicated ward for children with cancer by itself is a huge improvement as it helped in minimizing infection leading to better outcome. In addition to that, according to Martha and Selam, improvements in the area of provision of medication, only a maximum of two patients being admitted in a single room (which previously ranged from six to eight patients per room), each patient room equipped with its own bathroom (previously which was two bathrooms for 34 patients) were some of the improvements.

CHAPTER FIVE: DISCUSSION

This chapter of the paper discusses the results of the study by linking them to relevant literatures in the area. The discussion focuses on the themes that were identified by the findings of the study presented in the previous chapter and answers the research questions presented in the first chapter. The discussion will enable to understand the psychological, social and physical impacts of childhood cancer on participant parents as well as shows how parents had coped with the impacts.

A child's illness is an issue that cannot be seen without the context of the family and in this case, parents. According to Lowe (1997) health is not an experience specific only to an individual but within the framework of the community, group, and organization (as cited in Hutchison, 1999, p. 85) which, according to Sperry (2006) is common in the healthcare system, where bio-medical model takes precedence, integrated mind and body treatment tend lack (as cited in Atkinsa, Colville & John, 2011, p. 134). Therefore, this study shows how a child's illness affects parents from psychological and social arenas.

5.1. Psychological Impact of Childhood Cancer on Parents

The results of the study showed that participant parents of children with cancer experienced shock, fear, worry, stress, sadness, hopelessness, guilt, numbness, disbelief and difficulty of accepting child's diagnosis. In line with that, Jones (2006 as cited in Jones, 2012, p. 214) had indicated that most parents experience hopelessness, depression, sense of dishonest and guilt as a result of their child illness. Similarly, American Cancer Society (2012, How do parents usually react to a child's cancer diagnosis? section, para. 1) asserted that emotions of shock, disbelief, anger, fear, guilt, sadness and anxiety were common experiences of parents when they hear the diagnosis of their child. However, in contrast to Manne, Duhamel and Redd (2000), Jones (2006) and Boman (2003), the study had not found out sense of dishonesty, depression prolonged and complicated mourning among participants (as cited in Jones, 2012, p. 214).

The results of the study indicated that the emotional reactions that participant parents experienced were not only when hearing the initial diagnosis of their child but throughout the treatment process. The results of the study also revealed that several factors such as cost of medical treatment and diagnosis, communication about child's diagnosis, awareness and perception about the disease and sudden onset of the disease were found to aggravate the emotional reactions study participants had experienced. Similarly, American Cancer Society (2012, How do parents usually react to a child's cancer diagnosis? section, para. 2-19) had also expressed different scenarios would make parents experience the different emotional reactions.

5.2. Social Impact of Childhood Cancer on Parents

Findings of the study reveal that diagnosis of a child with cancer had social impact on participant parents. Changes in social roles including family roles, changes in responsibilities of parents, changes in marital relationship, and economic impact were the indentified social impacts participant parents had experienced. Economic impact was found in this study to be a major concern among parents and was also a common factor among the different issues addressed. This goes in line with the proposition of of Jones (2012, p. 215), Khoury, Huijer and Doumit (2013, pp. 18-19) and Bona, et al, (2014, p. 598) had that chronic illnesses such as cancer brings change in family roles, addition of responsibilities, marital disruptions, change in quality of life and economic impacts.

5.2.1. Impacts on Social Roles

In respect to changes in their family roles, the results of the study indicate that inability to provide for family as a major impact identified by study participants. In the family system, thirteen participants were breadwinners while one participant shares the responsibility with her spouse. Majority of the participants (thirteen) were engaged in farming and one participant in weaving. As a result of their respective children's diagnosis illness with cancer, study participants roles as provider to their families had changed to that of care giver. In addition to role change, the result of the study shows that a child's illness with cancer adds responsibility on parents as care providers for the sick child. Similarly, Jones (2012, p. 215) asserts that diagnosis of a child with cancer changes parents role and add additional roles of "advocates, councilors, and medical technicians". Likewise, Khoury, Huijer and Doumit (2013, p. 19) also stress that diagnosis of a child with cancer adds responsibilities to both parents with fathers being financially responsible and mothers with taking care of the household. Likewise, in this study, in instances where children were admitted and mothers were the primary care providers in four families, fathers were responsible for financial aspects of the family while mothers were responsible in providing care for their sick child. In contrast to the literatures, there were instances where fathers were responsible for provision of care for their sick children while mothers were responsible for the financial aspects and managing their household.

Another result of the study shows that as a result of child's illness, societal and community roles of all study participants had been affected. Societal roles that used to be carried out in their area of residence such as visiting sick people, attending social events such as weddings, funeral, christening and others had been affected. In line with that,

Pollock, et al. (2013, p. 107) had indicated that parents of children with cancer display negative social interactions. Similarly, Patterson and McCubbin (1983), Byrne and Cunningham (1985) and Kazak (1986) asserted the social isolation of parents of children with chronic illness (as cited in Tak & McCubbin, 2002, p. 192).

5.2.2. Impacts on Marital Relationship

The results of the study indicate that child's diagnosis with cancer had impact on the marital relationship of some participants. The impacts identified are related to communication where communication between the couples is only focused on child's health condition, argument as a result of financial challenges brought on the family, mistrust among the couples, and giving priority and focus to sick child. Similarly, researches conducted by Lawrence (2012, p. 21), Brody and Simmons (2007), Da Silva et al. (2010) and Yeh (2003) indicate that chronic illness such as cancer on children bring marital problems such as communication problems, argument, increased role strain, decreased relationship satisfaction, not spending time with each other, and divorce (as cited in Khoury, Huijer and Doumit, 2013, p. 20).

On the other hand, some study participant's case, child's illness had not impacted marital relationship of the participants rather they discuss and support each other. Similar to the research finding, Lawrence (2012, p. 21) had indicated that some marital relationships encounter increased closeness, cohesion and support among the couple. Similar to both findings, a research by Khoury, Huijer and Doumit (2013, p. 20) had revealed that child's illness had brought cohesion and closeness among the couple in most families who participated in the research while conflict only in one family.

5.2.3. Economic Impact

Another result of the study was economic impact of childhood cancer on parents. It is the finding of this study that participants had significantly been affected as a result of their income being disrupted as well as cost of medications and diagnostic investigations. Disruption of work had been identified across all participants and had an impact on the income of each household. However, economic impacts were more evident in eleven families than in others. The results of the study also indicated that loss of income had aggravated the financial impacts. Similarly, Bona, et al. (2014, p. 598) had identified work disruption, at least one parent leaving a job and loss of income due to work disruptions in all families to be the main economic impacts of childhood cancer on parents.

In relation medication and diagnostic investigations, the results indicate that some chemotherapeutic medications were available and others (main chemotherapy medications) were not available in the hospital (TASH). In addition to that, the cost of the medications had a huge financial burden on the participants especially when medications were bought from private pharmacies. In line with that, Alemayehu Hailu and Damene Hailemariam (2011, p. 7) had revealed that medical costs in case of cervical cancer patients in showed that tremendous financial burden on patients and families. Similarly, a study by Khoury, Huijer and Doumit (2013, p. 19) had also identified that in cancer treatment of children, financial matters to be a major issue.

5.3. Physical Impacts of Childhood Cancer on Parents

The results of the study indicate that participants had experienced physical impacts as a result of their children illness with cancer. The impacts identified are tiredness and lack of energy to perform tasks which had occurred as a result of sleep disturbance/lack of sleep which parents described as not having a "peaceful sleep" and "worrying while sleeping". Similarly, Klassen et al. (2008, p. 5888) indicated that sleep disturbances are common among parents of children with cancer and Pollock et al. (2013, p. 107) also assert that poor quality of sleep is associated with the stress level parents are in. Meltzer and Moore (2008, p. 279) have also identified that "nighttime care giving and worries about the child's illness" result in parent's sleep disruption which includes "poor sleep quality and shorter sleep quantity".

In addition to child's health condition, the results of the study indicate that, the environment in which parents spend time (hospital ward), and the conditions in which they sleep (sleeping on the floor on a mattress) are identified as factors that cause poor quality of sleep among study participants. Similarly, Young, et al (2002, p. 1838) had found out the conditions under which parents sleep have effects on the quality of sleep of parents.

Another result of the study that participants had experienced is loss of appetite leading to weight loss. Similarly, American Cancer Society (2012, Ways to improve coping section, para. 3) asserts that parents of children with cancer are likely to neglect daily routines such as eating, sleeping, and others that allow them to care for their child better.

The study result also revealed that childhood cancer exacerbated previous and existing medical conditions in two parents. In the case of this study, existing medical condition in one mother, diabetes, had been aggravated to a point where the mother had to be put on insulin injection. In the other participant's case, previous leg problem as a result of a bullet injury was aggravated associated with child's health issues. Similarly, Brehaut et al. (2004) and Raina et al. (2005) had stated that poor health condition to be common in parents of children with chronic illness (as cited in Meltzer & Moore 2008, p. 279).

5.4. Coping Mechanisms of Parents

In regards to how study participant's cope with the impacts they had faced, the results indicate that participants had used both problem-focused and emotion-focused coping styles. Problem-focused coping includes having free paper, selling properties and contracting out lands. While crying, praying, putting trust in higher power (God and Allah according to their respective religions), and "returning to self" were emotion-focused coping styles that were used by participants. In line with that, Hutchison (1999, p. 141) describes problem-focused coping style as taking action to alter a situation when the circumstance is viewed as controllable. Whereas emotion-focused copying style are used in circumstances where the prevailing view is that the situation is unchanged and people cope amend the manner or the meaning of the situation (Hutchison, 1999, p. 141).

Similarly, the findings of Norberg, Lindblad and Boman (2005, p. 970) revealed that parents more frequently used active problem focusing rather than avoidance behavior. Likewise, the results of this study indicate that participant parents had used active problem focused coping strategy such as selling their properties and contracting out lands to cope with economic problems they were faced with. In contrast to the study findings, Papastavrou, Charalambous and Tsangari (2012, p. 261) had revealed that majority of participant care givers in their research, had utilized emotionally focused coping strategies mainly avoidance or denial and wishful thinking. Whereas, the results of this study revealed that difficulty of accepting child's diagnosis with cancer to exist, the study had not identified avoidance or denial of child's diagnosis with cancer among study participants.

In coping with the challenges of economic burden, the result of the study showed participants had sold the cattle's and house and contracting out their lands. Similarly, Bona et al. (2014, p, 598) had found out that parents used strategies such as "reducing expenses by avoiding big purchases, incurring debt, selling property and organizing fundraising" as coping mechanisms.

The results show that participants had utilized different psychosocial supports to cope with the impacts brought by childhood cancer. The identified supports were social supports, organizational supports and supports from health care providers. In line with that, the results show that participants had received social support from family, friends, neighbors, 'idir' and from religious leaders. Similarly, Raz, Rot and Buchbinder (2012, p. 37) had identified that informal social supports from family members and social networks were found to increase parental coping. Likewise, American Cancer Society (2012, Ways to improve coping section, para. 8) stressed the importance social support such as family, religious institutions, place of work and neighborhoods in parental coping.

At organizational level, participants had also been supported, directly or indirectly, by different organizations including Tikur Anbessa Specialized Hospital (TASH), International Network for Cancer Treatment and Research - USA (INCTR-USA), Mother Tressa Missionary Shelter, Ye Matias Wondu Cancer Society, Fekat Circus Group and Tesfa Addis Parents Childhood Cancer Organization (TAPCCO). Similarly, Raz, Rot and Buchbinder (2012, p. 37) had found out those formal support systems such as health care professionals and health institutions were important for parental coping.

The results of the study indicate that majority of the supports provided were addressing the social impacts parents were facing as a result of child diagnosis with cancer. In addition to that, the supports were found to be inadequate.

In regards to psychological support, the result of the study showed that there was insufficient support for parents. Proper provision of information, also referred as medical counseling, was not consistent across study participants. Those participants who had been provided with precise information on child's diagnosis, treatments and side effects of medications had benefited. Similarly, Raz, Rot and Buchbinder (2012, p. 36) had found out that provision of clear information on diagnosis and treatment plan to parents to be an important step in enabling them to cope with impacts of childhood cancer. Similarly, Kästel, Enskär and Björk (2011, p. 291) stated that clear information to parents on the diagnosis and treatment of their child assist them in taking responsibility and making decisions.

5.5. Discussion summary

According to the family stress theory, any event whether positive or negative, will have an impact on families (Smith, et al., 2009, pp. 96-97). Similarly, as indicated in the findings and discussion parts of the study, childhood cancer had brought psychosocial impact on study participants. In addition to that, study participants had also experienced physical impacts as a result of their children's illness. In spite of all that, the study had also identified ways in which study participants had tried to cope with situations as well as the different supports that were available to them which corresponds with family stress theory which asserts that families can cope with a stressor event through utilizing resources available which could be within individuals in the family, friends and other family members, and from the community (Smith, et al., 2009, pp. 96-97).

Hutchison (1999, p. 85) asserts that there exists a relationship between physical, psychological health and social experiences of an individual. In line with that, the study had also found out that different factors associated child's illness with cancer had brought those impacts and interdependence between the impacts is observed. This signifies that, in case of this study, a childhood cancer does not only affect the diagnosed child but it also affects the parents. And parents are affected psychologically, socially and physically.

CHAPTER SIX: CONCLUSION AND SOCIAL WORK IMPLICATION

This chapter provides conclusion notes to the study and presents implications of the study from social work, research and policy perspectives.

6.1. Conclusion

This study was conducted to identify the psychosocial impacts of childhood cancer on parents with children diagnosed with cancer. It had the objective of identifying the psychological, social and physical impacts of childhood cancer as well as identifying how parents cope with the impacts.

The study was based on the perception and experience of participants who had children below the age of fifteen, diagnosed with cancer and following treatment at Pediatrics Hematology/Oncology unit of TASH either as in or out patient. Moreover, health care professionals were also included in the study as key informants.

Emotional reactions such as shock, fear, worry, stress and sadness were experienced by participants. Moreover, hopelessness, guilt, numbness, disbelief and difficulty of accepting child's diagnosis were also experienced by participants. The psychological impacts that study participants had experienced were not only associated with hearing child's diagnosis but were also related to the social impacts they have encountered.

Changes in social roles including family roles, changes in responsibilities of parents, changes in marital relationship, and economic impacts were the social impacts parents of children with cancer in this study had experienced. Among study participants, economic impacts of child's illness with cancer associated with disruption of work and cost of medical care were prominent.

Study participants had also experienced physical impacts, tiredness and lack of energy, as a result of child's illness with cancer. Participants exhibited the impacts as a result of sleep disturbance/lack of sleep associated with worrying about child's illness and the conditions and environments under which they sleep. In addition to that, the study had revealed that existing medical and previous conditions were aggravated as a result of child's illness with cancer in two study participants.

In addition, the study had also showed into the different ways study participant's cope with the impacts they had faced. In that regard, the study had revealed that participants used both problem-focused and emotion-focused coping styles. The problem-focused, specifically active problem focused, coping that were used include having free paper, selling properties and contracting out lands. While crying, praying, putting trust in higher power, and "returning to self" were the emotional-focused coping styles that were used by participants. In line with that, participants had different psychosocial supports that assisted them in coping with the impacts brought by childhood cancer. Supports from social networks, organizations and from health care providers were the identified support systems. However, psychological supports to parents were minimal. Although there were different social supports, they were not sufficient as well as not well organized.

In conclusion, childhood cancer had brought different psychological, social and physical impacts on study participant parents with children with cancer. In order to manage the different impacts, study participants had used both problem and emotion focused copying strategies. Moreover, different stakeholders involved had supported participants to cope although their involvements were not directly observed by parent participants. However, supports for parents were observed to be more inclined towards social dimension, the different psychological challenges were neglected. On top of that, participants had voiced economic challenges to be the major impact they had faced as a result of child's illness with cancer and the social supports lack organization and coordination. Furthermore, the different impacts observed on study participants had interdependent nature and should be observed together rather independently.

6.2. Social Work Implication

The findings of the psychosocial impact of childhood cancer on parents with children diagnosed with cancer study present social work implications which are organized in four major areas; practice, education, research and policy implications and are presented below.

6.2.1. Practice Implication

As the findings of the study show, parents with children diagnosed with cancer were faced with different psychological, social and physical impacts and had tried to cope as much as possible with those challenges using the resources available around them. However, as the impacts are diverse and sever and long lasting, social work intervention is also necessary in the area of childhood cancer for parents. In that regard, social work intervention in a health setting is mandatory in the areas of:

Awareness creation is important in the area of childhood cancer and its impact on children as well as on parents and families through utilization of different means of communication for all stakeholders,

Both psychological and social supports should be available for parents of children diagnosed with cancer. In line with that, the existing support systems from health care professionals, different organizations and volunteers should be encouraged and strengthened,

In provision of support to parents with children diagnosed with cancer, social workers need to work with different interdisciplinary teams including physicians, nurses, psychologist, and others,

Establishing psychosocial support unit in the health institution and social workers should collaborate with concerned organizations and proved supportive trainings for parents in the areas of managing stress, developing their coping skills and other relevant skill trainings.

6.2.2. Education Implication

In regards to education, social work education should incorporate psychosocial support in the health sector and specifically in the area of working with families of children with chronic diseases. Moreover, the health education system should also incorporate addressing the psychosocial aspects patients and that of the family system in the curriculum.

6.2.3. Research Implication

There is lack of research in the area of childhood cancer in general and specifically in relation to psychosocial effect on parents. As primary care providers and responsible in making decisions in all aspects of their children, parents are challenged and severely affected due to their child's illness. Additional researches in the area not incorporated in this study, such as impacts on spirituality of parents of children with cancer that will enable to understand the situation in a different perspective. Furthermore, the existence of more researches will further direct the health care system to be integrative and family centered.

6.2.4. Policy Implication

At policy level, recognizing burden of non-communicable diseases and incorporating prevention and treatment aspects in the health policy is commendable. However, in the area of childhood cancer, focus should be given to early diagnosis rather than prevention as cancer in children is not preventable. Therefore, the health policy should try to create condition (training health care providers, availability of diagnostic equipment's, and others) in which early diagnosis of cancer in children is possible. In addition to that, availability of sufficient and consistent cancer treatments (chemotherapeutic and other subsidiary medications) should be established as well. As cancer treatment medications are very expensive, measures that accommodate medication provision and affordability of the costs by families should be established considering socio-economic status of families as well sustainability of treatments.

In areas of childhood illnesses in general and cancer in particular, the treatment take a long time and that has its own impact on parent's psychological, social, financial, and health aspects. Therefore, policies should incorporate integrative and family centered services for children and their families. In line with that, the bio-medical model that governs Ethiopia's health care system should also focus on seeing the whole (psychological, social, biological and spiritual) dimensions of a person and address the issues accordingly. In addition, as TASH is the only centre providing cancer diagnosis and treatment for children, it does not have pediatric oncologist. Concerned government institutions should work to increase the number of health care professionals in the area.

As a health and education institution, TASH should also work in collaboration with school of social work and psychology departments of Addis Ababa University to provide services for parents of children with cancer.

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Annexes

Annex 1

Informed Consent

My name is Atsednesh Getachew, and I am a post graduate student at Addis Ababa University, School of Social Work. I am conducting a qualitative study on the psychosocial impact of childhood cancer on parents with children diagnosed with cancer. This study is conducted as partial fulfillment of my master's degree in social work. The purpose of this study is to understand the impact childhood cancer on parents and how parents try to cope with the challenges they are faced with.

The study's findings are believed to serve as a starting step on identifying the psychosocial challenges parents face as a result of their child's health situation. Secondly, it will increase awareness of the challenges parents face as a result of their child's diagnosis with cancer. On top of that, it will also assist health and other concerned institutions who are working in the area of childhood cancer directly or indirectly.

Cancer poses physical, psychological, social and economic impacts to parents when their child is diagnosed with the disease. In line with that, an in-depth study of the psychosocial impact of childhood cancer on parents as well as their coping mechanisms and identifying the types psychosocial support provided to the parents by health institution, family members and social support systems will be able to provide an insight to a situation not so far considered and it will also serve as a source for further investigation for other researches in the area.

Your participation in the study is much appreciated and will consist of an interview or focus group discussion. It is estimated that the in-depth interview will take one hour and half. Please know that this interview will be audio recorded to assist me to analyze it later on. The focus group discussion is also estimated to take one and half up to two hours and it will also be audio recorded for later analysis. I will do my best to ensure that your participation is kept confidential but please know that the rule of confidentiality shall be breached in cases where it is found necessary to prevent serious, foreseeable, and imminent harm to you or others or when laws or regulations require disclosure without your consent. You may choose skip any question that you are not interested to respond or quit the interview session at any time. By all means, please know that your participation or not participating in the study will not in any form affect your child from getting the service he or she is currently receiving.

If you have any question or concerns, you may contact the researcher by the following telephone number 0911107328 Atsednesh Getachew or my Advisor Dr. Ashenafi Hagos by the phone number 0911 099888. By signing below you agree that you have read and understood the above information, and would be interested in participating in this study.

Name ______________________

Signature ______________________

Annex 2

In depth interview guide

Part 1 – Socio demographic data

Age: _____ Sex _____ Religion _________ Area of residence/region _____________

Number of children ___________

Marital status: _____________ Educational status: ______________

Employment background:- _____________ Main means of income/supporting _____________

Part II – Information of child

Age ________ Sex ________ Education status/grade ____ Diagnosis time/how long _____

Part III – Interview guide

1. Could you please tell me about your child before diagnosis with cancer?

   Probing questions:

   - School and neighborhood activity, school performance, interaction with family and friends

2. Could you please tell me about the situation when your child was diagnosed with cancer?

(information about treatment, side effects, what to do during and after treatment, etc.)

- How you have come about to know all the information you have (who provides the information)

5. In what ways does your child's illness has brought change in you and your spouse?

   Probing questions:

   - What type of physical changes you have observed in yourself and spouse? (Weight loss, sleep disturbance, loss of appetite, etc.)
   - What type of emotions/feelings you have observed? (Sadness, anger, fear, hopelessness, guilt, etc.)
   - What type of changes in your and spouses social life have you have observed? (Decreased or lack of social activity such as visiting relatives and sick people, attending weddings or other occasions you and your spouse are invited, disruption or resigning from work, financial challenges, etc.)
   - Changes in marital relationship (not spending time with spouse/partner, lack of communication, etc.)
   - Changes in family responsibility (taking care of house hold chores, looking after other children, etc.)

6. How do you try to cope with all the changes you have mentioned in you and your spouse

Probing questions:

- When did he/she start to get sick, types of symptoms
- How and where did you found out
- What were the steps or procedures taken to initiate treatment?
- How long has your child been admitted/ or following up treatment?

3. Could you please tell me your experience when you first have been told your child has cancer?

Probing questions:

- What were your feelings/reactions?
- What was your spouse experience/feeling/reaction?
- What were your children and other family member's feelings/experience/reaction?
- What do you feel now that your child has cancer?

4. Could you please tell me what you know about cancer in children?

Probing questions:

- What did you know about cancer in children before your child's diagnosis?
- What did you know about cancer in children after (now) your child's diagnosis?
- What information do you have regarding diagnostic procedures and treatment

Probing questions:

- What kind of support do you get that enables you to manage the challenges associated with your child's illness?
- And who provides those supports for you? In what way has that helped

Annex 3

Focus group discussion interview guide

Part 1 – Socio demographic data

Age: _____ Sex _____ Religion _________ Area of residence/region _______________

Number of children ___________

Marital status: ______________ Educational status: _______________

Employment background:- ______________ Main means of income/supporting ______________

Part II – Information of child

Age ________ Sex ________ Education status/grade ____ Diagnosis time/how long _____

1. What does having a child with cancer mean to parents?
2. What type of changes parents with a child with cancer encounter as a result of the disease?

   Probing questions:

   - Type of physical changes (Weight loss, sleep disturbance, loss of appetite, etc.)
   - Type of emotions/feelings (Sadness, anger, fear, hopelessness, guilt, etc.)
   - Type of social changes (Decreased or lack of social activity such as visiting relatives and sick people, attending weddings or other occasions you and your

spouse are invited, disruption or resigning from work, financial challenges, etc.)

- Changes in marital relationship (not spending time with spouse/partner, lack of communication, etc.)
- Changes in family responsibility (taking care of house hold chores, looking after other children, etc.)

3. How do parents with a child with cancer try to cope with the challenges brought by the disease?

   Probing questions:

   - Type of support that enables them to cope with different challenges? (From family members, from health institutions, from other institutions)
   - What kind of support do you think need to be available for parents with children diagnosed with cancer that will enable them to cope better with the impact?

Annex 4

Key informant interview guide

Age: _____ Sex ____ Religion _________

Marital status: _____________

Educational level: _______________ Profession ___________

Year of experience in pediatric oncology unit: _______________

1. What are the basic services available at the hospital for children and parents with children diagnosed with cancer?
    - Types of psychosocial support services
    - What are the challenges
    - Who are the stakeholders in the service delivery & what are their roles
2. What are the changes that have occurred in service delivery in pediatric oncology in the past three years?
3. In your experience, what type of psychological impacts have you observed on parents with children diagnosed with cancer?

Pediatrics Hematology/Oncology unit head

1. Could you please tell me about pediatrics hematology unit
    - Its establishment,

- basic services available at the hospital for children and parents with children diagnosed with cancer, what are the challenges
- Who are the stakeholders in the service delivery & what are their roles
- What are the changes that have occurred in service delivery in pediatric oncology in the past three years?

2. Could you please tell me at what stage of the cancer progression do parents bring their children to health care facilities, in this case Tikur Anbessa Specialized Teaching and Referral Hospital?
    - What are the criteria's and procedures utilized to differentiate between in and out patients?

ስለዚህ የጥናት ፅሁፍ ተጨማሪ ማብራሪ ከፈለጉ እኔን (0911 107328) ወይንም የዚህ የጥናት ፅሁፍ አማካሪን ዶ/ር አሸናፊ ሀጐስን (0911099888) ማነጋገር ይችላሉ፡፡ ፈቃደኛ ከሆኑ አባክዎትን ከላይ የተዘረዘረው አንብበው ስለመረዳትዎ እና ፈቃኝነትዎን ለመግለጽ ስም እና ፊርማዎትን ከታች በተጠቀሰው ቦታ ያስፍሩልኝ፡፡

ስም________________ ፊርማ__________________

Annex 6

ከወላጆች ጋር ለቃለ መጠይቁ የተዘጋጁ ጥያቄዎች

ክፍል - 1 የተሳታፊ መረጃ

እድሜ ፆታ የልጆች ብዛት

ሀይማኖት የመጡበት አካባቢ

የጋብቻ ሁኔታ፡- የትምህርት ሁኔታ፡-

የሥራ/የቅጥር ሁኔታ፡- የቤተሰቡ ዋና የገቢ ምንጭ

ክፍል 2 የልጅ መረጃ

እድሜ ፆታ

የትምህርት ደረጃ (ክፍል)

ካንሠር እንዳለባት/እንዳለበት የታወቀበት ጊዜ ____________________

ክፍል 3 ጥያቄዎች

1. ስለ ልጆት አንዳንድ ነገሮች ቢነግሩኝ
    - በትምህርት ቤት፣ በሰፈር አካባቢ፣ በቤተሰብ እና በጓደኞች አካባቢ ስለአላት/ለው እንቅስቃሴ
2. ልጆት የካንሠር ህመም እንዳለው/ላት ስታወቅ ስለነበረው ሁኔታ ቢያስረዱኝ፣
    - መቼ ህመሙ እንደጀምረው/ መራት፣ እንዴት፣ የት እንደታወቀ
    - ህክምናውን ለመጀመር የተደረጉ ዝግጅቶች
    - ህክምናውን መከታተል ከጀመረ/ች ስንት ጊዜ ሆነው/ናት፣ ስንት ጊዜ ተኝቶ/ታ ታከመ/ች
3. ልጆት ካንሠር እንዳለበት/ባት ለመጀመሪያ ግዜ ሲነገርዎት ስለነበረው ሁኔታ ቢያስረዱኝ፣
    - ምን ተሰማዎት/ምን አደረጉ

  - ባለቤትዎ፣ ሌሎች የቤተሰቡ አካላት ምን ተሰማቸው/ምን አደረጉ
  - በአሁኑ ሰአት ምን ይሰማዎታል

4. በልጆች ላይ ስለሚከሰት ካንሰር ያለዎት ግንዛቤ ቢያስረዱኝ
   - ልጅት ከመታመሙ/ሟ በፊት ምን ነበር? አሁንስ?
   - ስለ ህክምናው የምርመራ አይነቶች እና መድኃኒቶች ምን አይነት መረጃ አልዎት?
   - አላስፈላጊ የመድሀኒቱ የጐንዮg ጉዳቶች፣ ከምርመራ እና መድሀኒት ከመወሰዱ በፊት እና በኋላ መደረግ ስለሚገባቸው ሁኔታዎች
   - እነዚህን መረጃዎች እንዴት አወቋቸው
5. የልጅት ህመም በእርስዎና በባለቤትዎት ላይ በምን መልኩ ተፅእኖ አምጥቶአል ብለው ያስባሉ?
   - በአካላዊ ጤና ላይ ያለው ተፅእኖ (ክብደትመቀነስ፣ እንቅልፍ መዛባት፣ ምግብ ፍላጎት መቀነስ፣ ወዘተ)
   - ስነ ልቦና ላይ ያለው ተፅእኖ (ማዘን፣ መተከዝ፣ ተስፋ መቁረጥ፣ ፍርሀት፣ ወዘተ)
   - በማህበራዊ ህይወት ላይ ያለው ተፅእኖ/ጫና (የታመሙን መጠየቅ፣ ማስተዛዘን፣ ስራ መስተጓጐል፣ የገንዘብ ጫና፣ ወዘተ)
   - በትዳር ላይ ያለው ተፅእኖ/ጫና (በቂ ግዜ አለመስጠት ወዘተ)
   - በቤተሰብ ሀላፊነት ላይ ያለው ተፅእኖ/ጫና (ልጆቻችሁን የመንከባከብ ኃላፊነት፣ የቤት ስራ ኃላፊነት፣ ወዘተ)
6. የጠቀሷቸውን ተፅእኖዎች ለመቅረፍ ወይንም ለመቀነስ እርስዎ እና ባለቤትዎ ምን አደረጉ
   - የተጠቀማችኋቸው ዘዴዎች ምን ለውጥ አመጣልዎት?
   - የጠቀሷቸውን ተፅእኖዎች ለመቋቋም እንዲችሉ ከሌሎች አካላት የተደረልዎት እገዛ አለ? ምን አይነት፣ እነማን ናቸው እያገዙት ያሉት (ጤና ባለሙያዎች፣ የበጐ አድራጐት ድርጅቶች፣ ቤተሰቦች፣ የሀይማኖት ተቋማት)፣ በምን መልኩ እንዲቋቋሙ አግዞታል

Annex 7

የመወያያ ጥያቄዎች (focus group discussion)

ክፍል፡ 1 የተሳታፊ መረጃ

እድሜ ፆታ የልጆች ብዛት

ሀይማኖት የመጡበት አካባቢ

የጋብቻ ሁኔታ፡- የትምህርት ሁኔታ፡-

የሥራ/የቅጥር ሁኔታ፡- የቤተሰቡ ዋና የገቢ ምንጭ

ክፍል 2 የልጅ መረጃ

እድሜ ፆታ

የትምህርት ደረጃ (ክፍል)

ካንሠር እንዳለባት/እንዳለበት የታወቀበት ጊዜ

ክፍል፡ 3

1. ለወላጆች የካንሰር ህመምተኛ ልጅ መኖር ማለት ምን ማለት ነው?
    - ካንሰር ምንማለት ነው?
2. በልጆች ላይ የሚከሰት የካንሰር ህመም ወላጆች ላይ ምን አይነት ተፅእኖ/ጫና ያጋጥማቸዋል?
    - በአካላዊ ጤና ላይ ያለው ተፅእኖ (ክብደትመቀነስ፣ እንቅልፍ መዘባት፣ ምግብ ፍላጎት መቀነስ፣ ወዘተ)
    - ስነ ልቦና ላይ ያለው ተፅእኖ (ማዘን፣ መተከዝ፣ ተስፋ መቁረጥ፣ ፍርሀት፣ ወዘተ)
    - በማህበራዊ ህይወት ላይ ያለው ተፅእኖ/ጫና (የታመሙን መጠየቅ፣ ማስተዛዘን፣ ስራ መስተጓጎል፣ የገንዘብ ጫና፣ ወዘተ)

   - በትዳር ላይ ያለው ተፅእኖ/ጫና (በቂ ግዜ አለመስጠት ወዘተ)
   - በቤተሰብ ሀላፊነት ላይ ያለው ተፅእኖ/ጫና (ልጆቻችሁን የመንከባከብ ኃላፊነት፣ የቤት ስራ ኃላፊነት፣ ወዘተ)

3. የተጠቀሱትን ተፅእኖዎች ወላጆች እንዴ ይቋቋሟሉ (ለመቅረፍ ወይንም ለመቀነስ ምን ያደርጋሉ)
   - የተጠቀሱትን ተፅእኖዎች ለመቋቋም እንዲችሉ ከሌሎች አካላት ምን አይነት እገዛ መኖር አለበት? (ጤና ባለሙያዎች፣ የበጎ አድራጎት ድርጅቶች፣ ቤተሰቦች፣ የሀይማኖት ተቋማት)
   - ለወላጆች ምን አይነት እገዛ መኖር አለበት

Glossary

Contract out farm land: - is when a farmer bids out his/her farm land for another farmer for an agreed amount of money

Family: - siblings, grandparents and other extended members who provide support to the parents in the home and/or hospital setting

Free paper: - a document given by a local administration that states that a person is not able to pay for medical care as a result of his/her low socio-economic stand.

Free patient: - a person who is receiving medical service available in a government owned institution without payment

Health personnel: - an individual who provides medical service to the cancer patient in a health facility

Hematology: - area of medicine that focuses on diseases of blood and blood forming organs

Idir: - A voluntary self-help association which serve as a socio-economic insurance at times of death and carry out various local development activities

Inpatient – children admitted and on treatment in the pediatrics hematology/oncology unit.

'Kere':- A term used in Wollo to refer to idir

Oncology: - field of medicine that study about treatment of tumors

Outpatient – children following cancer treatment while they are at home or at a shelter

Parents: - biological or legal guardians of a child diagnosed with cancer

Pediatrics: - subdivision of medicine that deals with provision of treatment to infants and children

Private pharmacies: - pharmacies owned by individuals and located outside of Tikur Anbessa Specialized Hospital

Sharing farm land: - is when a farmer who owns a farm land agrees with another farmer who will be farming the land and share the yield equally amongst themselves.

'Tenecha': – A term used in Arusi to refer to a tumor