Jimma University

College of Social Sciences and Humanities

School of Social Work

The Socio-Economic Determinants of Children's Cancer Treatment Adherence; The Case of Jimma Medical Center.

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A Research Submitted to the School of Social Work in Partial Fulfilment of the Degree of Masters of Social Work

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July, 2021

Jimma, Ethiopia

Declaration

I, the undersigned, declare that this thesis is my original work and has not been presented for any degree in any other university and all the sources of materials used for this research project have been duly acknowledged.

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Confirmation and Approval

This thesis has been submitted for examination with my approval as a thesis advisor.

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Acronyms & Abbreviation

AT	Abandonment of treatment
TASH	Tikur Anbassa Specialized Hospital
JUMC	Jimma University Medical Center
FGD	Focus Group Discussion
NCID	National Cancer Institution Dictionary
LMICs	Low and Middle-Income Countries
W H O	World Health Organization
SHRQoL	Social Health-Related Quality of Life
TAPCCO	Tesfa Addis Parent Childhood Cancer Organization
TA	Treatment Adherence
JUMCCO	Jimma University Medical Center Clinical Officer
EMOH	Ethiopian Ministry of Health

Acknowledgements

First of all, I would like to extend my sincere gratitude to my advisors Mr. Tullu Hajjii and Mrs. Rahel Gebremichael who gave me insightful comments and advice. Without their continuing support and supervision, this thesis was not come into being. Second, I would like to express my immense gratitude to all those people who had given me their valuable encouragement and assistance and who have shared their knowledge with me during my study. I am also grateful to all the research participants for their cooperation and free sharing of information. And finally, my sincere thanks go to my family and all my friends. Without their great love and concern, I could not have completed this thesis.

Abstract

The study aims to identify how the socio-economic determinants affects children's cancer treatment adherence, at Jimma University Medical Center Oromia national regional state, southwestern Ethiopia. Since this study gives emphasis on understanding individual experience about the treatment and treatment adherence; Qualitative research approach adopted to better understand the topic. Non-probability sampling technique from which purposive sampling was specifically employed to select the participant. To this end, both primary and secondary data was collected through semi-structured interview, FGDs, observation and reviewing different documents. The study designed to deeply explore and describe the impacts of socioeconomic determinants of children's cancer treatment adherence. The data analysis was began in categorizing and putting data into theme Voluntary consent was taken and participant informed withdraw at any time, also trustworthy kept by good rapport with participant. Finding of the study revealed that, most of children come to the medical center are from low socio-economic status and low awareness about chronic diseases and due to this the families or guardians of vulnerable children to cancer don't adhere to treatment. They come from furthest rural area of south west part of the country by itself is a challenge, they don't know modern life and they can't afford the living cost and medical expense.. That make many clients (patient) to non-adherence treatment. Shortage of chronic chemotherapy drugs, no training to health care service providers, delaying of repairing equipment in the unit and absence of out-patients place to those have fellow up. This and other challenges to offer treatment in the unit.

Keywords: *Adherence, Abandonment, Cancer, Oncology, Childhood, and Pediatric, family,*

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CHAPTER ONE

1 Introduction

Globally, the number of new cancer cases in all age groups will increase from 12.7 million in 2008 to 22.2 million by 2030. An increasing proportion of this cancer burden falls on low and middle-income countries (LMICs). Demographic change, prevalence of infectious diseases and a transition in risk factors resulting from globalization of economies and behaviors contributed for the high burden of cancer in LMICs (Malede, 2019). With the advancement in diagnosis, treatment and supportive care in pediatric patients with cancer, there have been dramatic improvement in survival rates in developed nations, where 80% of the children with cancer achieve cure (Munlima Hazarika et al., 2019*).*

But picture is not so promising in developing and underdeveloped countries, which accounts for 70%-80% of the nearly 2,50,000 newly diagnosed childhood cancer cases each year; and, often less than 25% of them surviving (Munlima Hazarika et al.,2019*).* Refusal and abandonment of treatment is often considered as an important reason for inferior survival outcome in childhood cancers in low and middle-income countries (Arora et al., 2007; & Bonilla et al., 2009).

In addition, even when adequate oncologic treatments are available, disparities in education and socioeconomic conditions, coupled with inefficient or suboptimal health care delivery, result in poor outcomes for children diagnosed with cancer in LMIC. The counties like Ethiopia in Africa (sub-Saharan Africa) faces many of these challenges. (Arora et al., 2007, & Bonilla et al., 2009).

In Ethiopia, national data on prevalence and incidence of cancer are lacking. However, extrapolation from clinical records of Tikur Anbessa Specialized Hospital (TASH) Radiotherapy

Centre estimates that there are 120,500 new cancer cases and approximately 6000 new cases of pediatric cancer each year. When we come to the study area the clinical records of Jimma medical center from its beginning pediatric childhood cancer treatment admitted 443 clients after its starting and it estimated 120 new cases of pediatric cancer each year. Most of the pediatric cancer patients present with advanced disease and there is a high rate of abandonment of treatment which leads to high mortality rates (JMC, 2020).

According to the World Health Organization (WHO), non-adherence to the medical regimen consists a major clinical problem in the management of patients with chronic illness. Rates of non-adherence with any medication treatment may vary from 15% to 93%, with an average estimated rate of 50%. Cancer is a group of diseases of multifactorial origin with increasing worldwide incidence and mortality, thus necessitating intersectional actions for its control when there are limited financial resources (NCI, 2009). Cancer treatment is multimodal, involving surgery, radiotherapy, and chemotherapy, and this is expensive. However, there are large gaps in cancer treatment outcomes because of differences among countries in socioeconomic development and access to health services (NCI, 2010).

For the purposes of the study, I was adopted the national cancer institution (NCI) definition of cancer as the basis for its understanding of treatment adherence: “a term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer. Carcinoma is a cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukemia is a cancer that starts in blood-forming tissue, such as the bone marrow, and causes large numbers of abnormal blood cells to be

produced and enter the blood. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system. Central nervous system cancers are cancers that begin in the tissues of the brain and spinal cord, (NC I, 2010).

The outcome of pediatric cancer therapy in the developed country is good, but in developing countries like Nigeria pediatric cancer treatment is characterized by late presentation, presences of co-morbidities and outright refusal of investigation and initiation or continuation of treatment this might be because of socio economic reasons (Ishaya & Adah, 2016). There are many types of cancer treatment modalities, which include surgery, radiation therapy, chemotherapy, immunotherapy, targeted therapy, hormone therapy, stem cell transplant and precision medicine. Selection depends on the type and staging of the cancer diagnosis (Aziza, Julia, & Mary, 2013). By 2020 the World Health Organization predicts that there will be 16 million new cases of cancer every year, 70% of which will be in developing countries. Overall, the developing world will suffer the heaviest burden of 8.8 million cases of cancer, with Sub-Saharan Africa accounting for more than 1 million cases. Cancer is already a real and relevant problem in Africa and yet it threatens to become a pandemic of unstoppable proportions within the next decade if we do not act now.(Psycho-oncology, 2019)

The impact of cancer is far greater than the number of cases would suggest. Regardless of prognosis, the initial diagnosis of cancer is perceived as a life-threatening event, with over one-third of patients experiencing clinical anxiety and depression. Cancer is also distressing for the family, profoundly affecting both the family's daily functioning and economic situation. The economic shock includes both the loss of income and the expenses associated with health care costs (EMOH, 2015).

Socioeconomic Determinants of Treatment Adherence

In contrast to what is seen in the developed world, failure of treatment of childhood cancer is still a common occurrence in developing country with non-adherence of treatment often exceeding all other causes of failure. In the developed world, any refusal or abandonment is likely to lead to health and social services intervening and they may even take court action to ensure that the child receives treatment (Arora et al., 2007). Such state support and intervention are non-existent in large parts of the world, including in Ethiopia, so that treatment non adherence remain common events.

Chronic illness is an illness that persists over a long period and affects physical, emotional, intellectual, vocational, social, or spiritual functioning of an individual. Treating these illnesses is highly dependent on modification of life style of the patient which in turn dependent on socioeconomic issues Lee, Keeffe, (2011). So, treatment was be seen from legal, functional and social domains perspective. Emphasis was put on understanding the experiences of the patient as well as the family. The study set out to identify how the socioeconomic factors associated with TA among children diagnosed with malignancy. I was analyzed the socioeconomic determinants responsible for childhood cancer treatment non-adherence in a Jimma Medical Center south-west Ethiopia.

At Jimma Medical Center Oncology Unit cost free treatment is provided to all patients to some extent this includes medications, laboratory tests, diagnostic and imaging procedures, and other treatments, as well as food and shelter for the patients and their care providers. Despite this, treatment non-adherence happens not infrequently and the reasons for this remain to be identified. Non-adherence is not only leads to treatment failure but also misallocates healthcare resources, which are already limited not only in the setting of a developing country like Ethiopia,

but also in that of a charitable institution that depends on philanthropic contributions for its resources.

Study aims were to examine the socioeconomic determinants of children's cancer treatment adherence in this population of patients in Jimma Medical Center. I believe that information derived from this study help us to identify predictors for treatment non-adherence in settings, which may help to improve childhood cancer outcomes by allowing healthcare providers to institute appropriate and timely interventions.

1.1 Statement of the Problem

From the definition of health, only treating a client's illness, does not give wellbeing for the clients, it needs to handle the clients, mental, social and psychological perspective. The client's multifaceted parts, which are, psychological, biological and ecological aspects as a whole must be considered (Hutchison, 2010).

One of the most significant problems today for childhood cancer treatment is non-adherence of treatment or treatment abandonment. Effective diagnosis depends not only upon identifying physical symptoms of illness, but also in being able to identify physical symptoms that may have psychological or social origins requiring different treatment plans (Evans *et al.* 1991). In some cases, it does occur for progressive of diseases, fear or intolerance therapy side effect and some are for a variety of socio-economic reasons. This knowledge can lead to new ways of preventing and treating the disease. Treatment non-adherence in children with cancer has been defined as the failure to complete potentially curative therapy. There are studies globally on the cancer, for instance the study done by Munlima Hazarika et al., (2018) with the aim of describing pattern and implication of therapy abandonment and its impact on survival of childhood acute lymphoblastic leukemia at large tertiary care center in northern India. It

identifies long distance from treatment center was amongst the commonest reasons for treatment abandonment and also treatment refusal in his study. In addition, the study done by Ishaya and Adahin (2016) on the role of socioeconomic factors in abandonment of cancer treatment among pediatric patients in Jos Nigeria, tries to determine the association between socioeconomic factors and abandonment of pediatric patient treatment. As there finding in 2016, they get 63.4% of prevalence of abandonment which observed in developing country and identified major cause to abandonment as socioeconomic, parental occupation and maternal education (Ishaya & Adah 2016).

Accordingly, in Ethiopia there are a few research on the effect of socioeconomic factors contributing to the cancer patient children's treatment issues like research in (2018) to assess the incidence trend and projection of childhood cancer in Addis Ababa and to generate accurate data for future policy and treatment interventions by Amanuel Baley. By his finding the overall cancer incidence rate decreased significantly from 2012- 2016. Incidence rates decreased significantly in male, while in female the incidence rate was stable. And also, in our country other studies by Malede Berihun aimed to identify and resolve drug related problems and found the dosing problems which includes dosage too low and high were the top ranking (39.3%) of all drug related problems followed by needs additional therapy (27.2 %) and non-adherence (14.0%) in Pediatric Hematology/Oncology ward of Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia (2018). Another study on the magnitude, patterns and trends of pediatric malignancies by Yifru and Muluye at northwest part of Ethiopia they come with finding shows increasing childhood cancer cases over the years (2015).

Treatment adherence should be treated as more than just a medical issue. It involves social, political, financial, and environmental considerations that may often be outside the

control of the patients or their families. It is not only just related to the direct expenditures associated with the treatment, but also indirect costs, such as decreased income, as many parents become unemployed looking after the sick child (Mostert, Gunawan, Wolters, et al.2012).

In Guatemala, socioeconomic factors such as presence of running water and electricity, the numbers of rooms in the house, and paternal education were correlated with treatment abandonment (Sweet-Cordero, Antillon, Baez, et al.1999). The attitudes and beliefs of the parents of children are also influenced greatly by the community and those close to them and they may be convinced to stop or discontinue treatment. It has been reported in multiple studies from LMIC that socioeconomic and educational factors play a role in rates of treatment adherence (Srinivasan, Tiwari, Scott, Ramachandran, & Ramakrishnan, 2015).

A traditional nurse-driven transition intervention providing purely medical follow-up may fail to address psychosocial problems and thus does not fully empower patients and caregivers to improve their health. Moreover, it is crucial that interventions address both psychosocial and health issues, linking patients to community resources as well as collaborating with the health care team (Altfeld, Pavle, Rosenberg, Shure.2012). Including social workers in-between care interventions may provide improved linkages to health care and community-based services as well as greater psychosocial support that led to sustainable positive health outcomes. Indeed, studies have shown increased social work support services are associated with lower total hospital costs and increased probability of physician follow-up after discharge (Altfeld et al., 2012–2013). The information derived from this study help health care providers and health care service deliver institution to identify predictors for treatment non-adherence in settings,

which may help to improve childhood cancer outcomes by allowing healthcare providers to institute appropriate and timely interventions.

Generally, when we see the above topic which done in our country, they focus on the incidence trend and projection of childhood cancer and to identify and resolve drug related problems in pediatric Hematology or Oncology. So, there is a relatively few literatures on children's cancer treatment non-adherence impacts on pediatric cancer patient in Ethiopia. However, the issue of socio-economic determinants of childhood cancer patient treatment adherence in Ethiopia has not been studied so far particularly, in the Jimma Medical Center, Oromia Region south-western Ethiopia. Thus, this study was specifically conducted to understand the socioeconomic determinant of children's cancer treatment adherence in Jimma Medical Center who are attending treatment and leaving or discontinues treatment. Furthermore, this study was given an emphasis mainly on the social and economic factors which challenges childhood cancer patient and their family by interpreting individual stories and experiences as a patient, family and a member of the community. Cognizant to these, the study chooses to pursue explore on the socio-economic determinants of children's cancer treatment adherence, the case of Jimma Medical Center in Oromia, National Region, state, south-western Ethiopia.

Emphasis was put on understanding the socioeconomic factors may enforced patient to non-adherence of treatment those in Medical Center and those enforced to abandonment of treatment live in community. Those identified by the above researcher in their country and those not touched aspect of socioeconomic determinants which may contribute to child cancer treatment non adherence. Both patient and family perspectives were considered to have a full picture about the role of socio-economic factors contribute to childhood cancer treatment abandonment. Finally, since the focus of the study was on role of social and economic factors

contributing to treatment abandonment/adherence/, individual stories, views and reflections was given due emphasis.

1.2.Research Questions

The following research questions was addressed in this study. In order to achieve the stated specific objectives, the study was focus on answering the following questions.

1. What are social determinants challenge to offering children's treatment in the oncology unit?
2. What are economic determinants challenge to offering children's treatment in the oncology unit?
3. What is the impact of economic determinants on children's cancer treatment?
4. What is the role of social determinants on children's cancer treatment adherence?

1.3.1 General Objective

The main objective of this study was to explore the socio-economic determinants impact on children cancer treatment adherence. At Jimma Medical Center, Oromia national, regional, state, south west, Ethiopia.

1.3.2 Specific Objective

- ✓ To identify the social determinants challenges to offer children's cancer treatment in the oncology unit.
- ✓ To know Economic determinants, challenge to offer children's cancer treatment in the oncology unit.
- ✓ To know the effect of economic determinants on children's cancer treatment adherence
- ✓ To find out the influence of social determinants on children's treatment adherence

1.4 Significance of the Study

The rationale for social work involvement in medical services is straightforward: as Volland writes, "People who seek medical treatment still need guidance beyond the actual identification and treatment of a medical problem." (Volland, 1996) Social workers can help to identify unmet needs in patients with complex chronic illness and assist them in navigating the complex healthcare system and attaining optimal levels of functioning.

Thus, social work driven interventions social workers facilitating access to multidisciplinary care and interventions may potentially reduce readmission rates and medical service use, as well as facilitate linkage to community-based social services to increase the quality of transitional care. Yet little is known about the social work role in improving care transitions in developing country like Ethiopia. This study important in providing insight into how a social worker can potentially improve the transition experience and health outcomes for at-risk individual spatially children with cancer.

This study was having theoretical and practice significances. The treatment outcome of cancer patients depends on stage and types of the cancer, biology of tumor and patient factors. Accordingly, the ultimate goal of cancer treatment is to relief the pain and search for cure for the patient. To this end, the field is facing several challenges (Wajana et al., 2019). From those several challenges socioeconomic factors are the main reason. However, little research was conducted on the socio-economic determinants which enforce non-adherence (abandonment) of children's cancer treatment in developing countries.

The result from the study of socio-economic determinants of adherence of childhood cancer treatment which focus on issues directly contribute to children's cancer treatment abandonment which used by organizations and practitioner working in the area of children's

cancer treatment to develop strategies to facilitate and narrow abandonment of treatment gap in pediatric children's cancer treatment. It is crucial for health professionals both to assess the patient and foresee the possible causes of non-adherence and follow a policy for increasing medication adherence and achieving the best health outcome. Additionally, since the issue is under-researched with paucity of literatures, the study attempted to fill the gap and to serve as reference for researchers to conduct further study in the area of pediatric children's cancer treatment.

The study is input the legislative body from the government side and the humanitarian agencies working on the issue of childhood cancer treatment to set frameworks on how to improve and enhanced pediatric childhood cancer treatment in the future, given that legal provision of the county is improved or changed to officially support treatment schema as preferable durable solution.

1.5 Scope of the Study

The scope of this study was limited both in its content and area coverage. In its content, it is limited only to the assessment of socio-economic determinants contributing to children's cancer treatment adherence which enforce cancer patient children's to treatment abandonment in Jimma University Medical Center Pediatric Hematology Oncology Unit. This is because of a treatment non-adherence /abandonment challenge and contribute to treatment failure in the unit. In its area coverage, this study is limited to Jimma medical center. This is because it is the only referral center for critical and complicated health problems in south-western part of the country.

1.6.Operational definition

Adherence: The extent to which a person's behavior taking medication, following a diet, and/or executing lifestyle changes corresponds with the agreed recommendations from a healthcare provider.

Determinant: is any social and economic domains factors that influence health outcome of client

Parent:

Abandonment: is a failure to complete a program of potentially curative therapy

1.7.Organization of the Study

The paper has five chapters. The first chapter consists of introductory section, problem statement, study objectives and questions, and basic information about the study area. The second chapter deal with reviewing relevant literatures and touches on theories of the role of socio-economic factors contributing to childhood cancer treatment abandonment. The third chapter is all about the research method. It highlights the overall research design, study sample, data collection instruments and procedures, data analysis and presentation mechanisms, and ethical consideration to conduct the study. While the description of the data is presented in chapter four. The findings of the study, some conclusion and recommendations followed by chapter five.

CHAPTER TWO

2. Review of Related Literatures

2.1.The Notion of Treatment Adherence

Cancer is a general term used to refer to a condition in which the body's cells begin to grow and reproduce in an uncontrollable way. These cells can then invade and destroy healthy tissue, including organs. Cancer sometimes begins in one part of the body before spreading to other parts. Cancer refers to over 100 different diseases characterized by uncontrolled growth and spread of abnormal cells. Cancer arises from one single cell following abnormal changes in the cell's genetic material. These genetic changes affect the mechanisms that regulate normal cell growth and cell death leading to uncontrolled cell growth. The abnormal changes are caused by interactions between genetic and environmental factors (NCI, 2009).

Environmental factors include physical carcinogens (e.g., ionizing radiation), chemical carcinogens (e.g., asbestos, components of tobacco smoke and aflatoxins) and biological carcinogens (e.g., certain viruses, bacteria and parasites). Cancerous cells have a tendency to proliferate uncontrollably, invading neighboring tissues and eventually spreading to other parts of the body. Cancer can affect almost any part of the body. Carcinoma is the cancer that begins in the skin or tissues that line or cover organs (NCI, 2009).

Owing to its nature, cancer is difficult to treat, and cannot be eradicated at population level. However, it is possible to significantly reduce the effects of cancer on society if effective measures are put in place to control risk factors associated with cancer, promote early detection and offer good care to those affected (NCI, 2010).

Socioeconomic Determinants of Treatment Adherence

According to Globocan, (2012) estimates, about 40% of cancers are preventable. The risk factors for cancer are profoundly associated with socio-economic status, they are higher for populations with low socioeconomic status populations, where cancer survival is lower than in wealthier social settings. The risk factors for cancer can be broadly categorized into four types, namely behavioral risk factors, biological risk factors, environmental risk factors and genetic risk factors. Behavioral risk factors include tobacco use, harmful use of alcohol, unhealthy diet and physical inactivity. Biological factors include overweight, obesity, age, sex of the individual and genetic/hereditary make up. Environmental risks include exposure to environmental carcinogens such as chemicals, radiation and infectious agents (including certain viruses).

Risk factors for cancer among young people are in general unknown; however, certain genetic disorders as well as environmental factors have been shown to play a role. Studies have shown that congenital immune defects, fragile chromosomes (ataxia telangiectasia, Bloom syndrome, etc.), certain birth defects, high levels of ionizing radiation, race, ethnicity and infections are associated with an increased incidence of cancer, (Sara ,2014).

Children and teens with cancer are usually able to comprehend the seriousness of the disease and as a consequence can become quite distressed by the diagnosis. Additionally, they become upset about the loss of contact with peers, disruptions in school attendance and their inability to participate in their usual activities. Patients with adjustment disorder may display transient anxiety, mood symptoms, or conduct problems not severe enough to qualify for a full diagnosis of anxiety or major depression, for example. Irritability or sadness may worsen before each hospital visit, and sleep and appetite may be disrupted for a few days. There may be subjective feelings of an inability to cope and plan ahead. It is assumed that these responses would not have emerged without the stress of cancer (Datta et al 2019).

Socioeconomic Determinants of Treatment Adherence

Adherence with medication usage is defined as the proportion of prescribed doses of medication actually taken by a patient over a specified period of time. Compliance, a synonymous term which was commonly used in the past, implies a passive role and simply following the demands of a prescriber, and non-compliance has been regarded as associated with deviant or irrational behavior. The term "Adherence", implies an active role in collaboration with a prescriber, and "non-adherence" encompasses the diverse reasons for patients not following a treatment recommendation (Lee & Keeffe, 2011).

Refusal and abandonment of treatment is often considered as an important reason for poorer survival outcome in childhood cancers in low and middle-income countries (Arora et al., 2007). Treatment refusal and abandonment is the principal cause of therapy failure in children with cancer in the developing world. A complex interplay of biological, socio-economic and treatment-related factors underlies this problem. Interventions are likely to succeed when they try and address all of these issues simultaneously, as exemplified by the success of twinning programs linking resource-rich and resource-limited countries, (Arora, *et al*, 2010).

Also called malignance," A general condition of treatment abandonment within communities, when patient discontinues of disease directed therapy with curative intent when the providers and the parent agree that the potential for cure or definitive control are too low to justify continuation and failure to complete curative therapy. A special type of discontinuation of treatment that should be distinguished from treatment is having forgone curative treatment.

Abandonment of treatment was defined as the termination of care by the parent/caregiver and/or not presenting for scheduled treatment for four weeks or more from the scheduled date of treatment at the time of data record in line with International Society of Pediatric Oncology (SIOP) recommendation (Mostert et al., 2011). If a child returned for treatment after 4 weeks,

he/she was considered in treatment abandonment group for analysis. Refusal of treatment was defined as no initiation of treatment after the complete diagnosis of cancer.

2.1.1. Cancer in Africa

Cancer is a global problem accounting for almost 13% of all deaths worldwide. This equates to over 7 million people a year, more than is caused by HIV/AIDs, TB and malaria combined. Although the world is rightly focused on controlling the spread of these infectious diseases, we are ignoring the growing burden of cancer in developing countries. The global disparities in cancer are stark. African countries are the least able of all developing countries to cope with the challenge posed by cancer as a result of a lack of resources, awareness, trained professionals, support and basic infrastructure to combat this disease.

Most Africans have no access to cancer screening, early diagnosis, treatment of palliative care, and many African nations are without a single cancer specialist for the whole population. Furthermore, only 21 of Africa's 53 nations have any access to potentially lifesaving radiotherapy. Thus, cancer survival rates are often less than half those of more developed countries. Many African languages still do not have a word for cancer, and the common perception is that it is a disease of the wealthy world(Lax-pericall, et al., 2019).

By 2020 the World Health Organization predicts that there will be 16 million new cases of cancer every year, 70% of which will be in developing countries. Overall, the developing world will suffer the heaviest burden of 8.8 million cases of cancer, with Sub-Saharan Africa accounting for more than 1 million cases. Cancer is already a real and relevant problem in Africa and yet it threatens to become a pandemic of unstoppable proportions within the next decade if we do not act now.(Psycho-oncology et al., 2019)

2.1.2. The Situation of Cancer in Ethiopia

In Ethiopia, cancer accounts for about 5.8% of total national mortality. Although population-based data do not exist in the country except for Addis Ababa, it is estimated that the annual incidence of cancer is around 60,960 cases and the annual mortality is over 44,000. For people under the age of 75 years, the risk of being diagnosed with cancer is 11·3% and the risk of dying from the disease is 9·4%. The most prevalent cancers in Ethiopia among the adult population are breast cancer (30.2%), cancer of the cervix (13.4%) and colorectal cancer (5.7%). About two-thirds of reported annual cancer deaths occur among women (E.F MO H, 2015).

In 1993 the government of Ethiopia published the country's first health policy in 50 years, articulating a vision for the health care sector development. The policy fully reorganized the health services delivery system as contributing positively to the country's overall socioeconomic development efforts. Its major themes focused on:

- Democratization and decentralization of health system;
- Expanding the primary health care system and emphasizing preventive, promotional, and basic curative health services; and
- Encouraging partnerships and the participation of the community and nongovernmental actors.

In Ethiopia up to 80% of the population uses traditional medicine due to the cultural acceptability of healers and local pharmacopeias, the relatively low cost of traditional medicine and difficult access to modern health facilities. In 2000 only 9.45% of all deliveries in Ethiopia were attended by trained attendants and health workers. The rest were attended by traditional birth attendants or relatives (Kebede, Alemayehu, Binyam,& Yunis, (2014).

Religious practices play a large part in the healing process for Ethiopians such as praying and going to church. Holy water for Orthodox Christians (called '***tsebel***' in Amharic) or '***zemzem***' in the case of Moslems is also frequently used for a wide variety of illnesses. Ethiopians believe that holy water cures when it is drunk or bathed in (Kebede, Alemayehu, Binyam & Yunis, 2014).

According to the World Bank's Global HIV/AIDS Program, (2007) Ethiopia had only 1 medical doctor per 100,000 people. However, the World Health Organization in its 2006 World Health Report gives a figure of 1936 physicians (for 2003), which is about 2.6 per 100,000. There were 119 hospitals (12 in Addis Ababa alone) and 412 health centers in Ethiopia in 2005.Globalization is said to affect the country, with many educated professionals leaving.

2.1.3. Pattern of Cancer in Ethiopia

Over the past decades, malignancy was not considered as a public health problem in developing countries, particularly Ethiopia, because of the increased burden of infectious diseases. Although 70 % of pediatric tumors are sensitive to treatment, and survival rates approach 80 % in developed countries, greater than 80 % of affected children in Africa die from their disease (Hadley et al 20112, & Chirdan, et al 2002).

Mortality rates for most pediatric cancers are close to 100 % in developing countries, including Ethiopia. The commonest childhood malignancies encountered includes lymphomas, leukemia, soft tissue sarcomas, osteosarcoma and neuroblastoma (Sisay & Dagnachew, 2015).

2.1.4. Pediatric Oncology in Ethiopia

Based on extrapolating estimates from another East African nation, Tanzania, with an incidence of pediatric cancer of 134 cancer cases per million11, Ethiopia probably has close to 6,000 new cases of pediatric cancer each year. The commonest cancers seen at TASH include leukemia, lymphoma, retinoblastoma, Wilms's tumor and bone and soft tissue sarcomas. Most

children present late, with advanced disease, and in pain. With a per capita income of approximately US$2 a day, resources devoted to health and health care in Ethiopia are limited.

In contrast, the survival rate for children and adolescents diagnosed with the most treatable cancers, including leukemia, lymphoma, retinoblastoma and Wilma's tumor is rapidly approaching 90% in developed countries and close to 50% in South Africa. The situation in Ethiopia is similar to that of other countries with severely limited resources; children with cancer often receive incomplete, inadequate or no care and those with incurable disease are frequently sent home to die without palliative care. Ethiopia lacks trained medical personnel, adequate facilities, a sufficient supply of essential chemotherapy drugs and simple pain medications necessary to treat cancer patients. As a result, there is little public awareness that cancer can be cured, little public demand that health systems address cancer, and consequently, few governments medical resources devoted to cancer treatment (Aziza, et al 2013).

2.1.5. Child with cancer and child family care

Children with cancer as well as their parents are at increased risk for significant psychosocial difficulties during all phases of treatment, including survivorship (Steele, 2015). Direct, honest and timely communication with children, adolescents, and their families about the nature of the illness and prognosis is a cornerstone of pediatric cancer care and palliative care. The Standards for Psychosocial Care for Children with Cancer and Their Families provides the first evidence-based clinical standards for addressing the psychosocial care of pediatric cancer patients and their families, (Wiener, 2015). These standards recommend that:

• Youth with cancer and their families should receive routine and systematic assessment of their psychosocial needs during treatment and survivorship.

• High risk patients should be routinely monitored for neuropsychological deficits.

• Youth and family should have access to psychosocial interventions, including psychological interventions for invasive medical procedures, and psychiatry as needed.

When necessary, youth and families should receive developmentally appropriate end of life care, including bereavement support. Well-funded, larger pediatric cancer centers may have multiple mental health professionals integrated in the multidisciplinary medical team. In such centers, it is possible for several disciplines (child life specialists, psychologists, psychiatrists, social workers, spiritual leaders) to contribute simultaneously to the emotional well-being of children and their families (Wiener, 2015).

Children with cancer can experience decreased physical, emotional, and social health-related quality of life (SHRQoL) compared to healthy children. Poor family functioning in children with cancer has been shown to negatively influence a child's SHRQoL and impair their ability to properly adjust (Barakat, et al 2010). This supports the critical role of the family for children impacted by cancer. Children receiving active cancer therapy and cancer survivors experience increased impairments in behavioral and social domains compared to controls (Schultz et al 2007).

2.2. Roles of Social Worker at the Health Setting

Social workers in hospitals and medical centers provide frontline services to patients with conditions spanning the entire health care continuum. Currently social workers across the continuum of treatment services (outpatient, acute, chronic, crisis intervention, and counseling, advocacy and case management) will play their role. Participation in natural disasters, global and national challenges in line with the privatization of health-care and stress inflicted on patients and their families are the major role that social workers can be involved in it (NASW, 2005). Social worker in a medical team helps to solve social problems in individual patients and their

families, and the interaction between the patient and the family is the main role of social workers in health care for patients in order to obtain their health.

2.3.1. Roles of Medical Social Workers

Social workers have long facilitated meet the health-related needs of the chronically ill persons. Hospital social workers help patients and their families understand a particular illness, work through the emotions of a diagnosis, and provide counseling about the decisions that need to be made. Social workers are also essential members of interdisciplinary hospital teams. Working in concert with doctors, nurses, and allied health professionals, social workers sensitize other health care providers to the social and emotional aspects of a patient's illness. Hospital social workers use case management skills to help patients and their families address and resolve the social, financial and psychological problems related to their health condition. Job functions that a social worker might perform within a hospital include: (NASW, 2001).

- Initial screening and evaluation of patient and families;
- Comprehensive psychosocial assessment of patients;
- Helping patients and families understand the illness and treatment options, as well as consequences of various treatments or treatment refusal;
- Helping patients/families adjust to hospital admission; possible role changes; exploring emotional/social responses to illness and treatment;
- Educating patients on the roles of health care team members; assisting patients and families in communicating with one another and to members of health care team; interpreting information;
- Educating patients on the levels of health care (i.e. acute, sub- acute, home care); entitlements; community resources; and advance directives;

- Facilitating decision making on behalf of patients and families;
- Employing crisis Intervention;
- Diagnosing underlying mental illness; providing or making referrals for individual, family, and group psychotherapy;
- Educating hospital staff on patient psychosocial issues;
- Promoting communication and collaboration among health care team members;
- Coordinating patient discharge and continuity of care planning;
- Promoting patient navigation services;
- Arranging for resources/funds to finance medications, durable medical equipment, and other needed services;
- Ensuring communication and understanding about post-hospital care among patient, family and health care team members;
- Advocating for patient and family needs in different settings: inpatient, outpatient, home, and in the community and
- Championing the health care rights of patients through advocacy at the policy level.

2.2.1. Principles of Social Worker's Role

- ✓ Provides a physical environment that is supportive rather than challenging or crippling to the individual
- ✓ Treats each individual with respect
- ✓ Creates an atmosphere of growth for the individual
- ✓ Adopts a holistic perspective by recognizing the dynamic interplay of social, psychological, physical, and spiritual well-being

- ✓ Fosters a positive self-image for the residents through continued social contact, decision making opportunities, and independence (Perrin, & Polowy, 2008).

Specific key tasks of the social worker's duties generally include but are not limited to:

- ✓ Planning for pre-admission and discharge
- ✓ Providing psycho-social assessment and completion of relevant parts of the
- ✓ Participating (as a member of an interdisciplinary team) in resident care planning
- ✓ Counseling residents and their families
- ✓ Contacting and utilizing community resources on the resident's behalf and serving as a link between the resident and these resource systems when necessary
- ✓ Ensuring the social and emotional needs of each patient
- ✓ Stimulating social contact and interaction
- ✓ Promoting the maximum level of independence of each patient (Perrin, & Polowy, 2008).

2.2.2. Oncology Social Work

Oncology social work is a specialization in social work that addresses the psychosocial responses and needs of individuals and families affected by cancer. Emerging from a long tradition of social work in health care, the subspecialty of oncology social work flourished in the 20th century as biomedical advances transformed cancer from a terminal to a chronic disease. The conceptual foundations of oncology social work are found in a number of disciplines, including psychosocial oncology, an area of clinical practice and research that addresses the psychological, social, behavioral, spiritual, and other dynamics of cancer among individuals, families, and communities.

Through multi systemic and holistic practice, research, education, and advocacy, social workers are integral to adding to the knowledge base of cancer and the provision of comprehensive care to people with and affected by cancer. This chapter will introduce readers to the foundations of oncology social work and to social work's unique contributions to comprehensive and integrated cancer care (Daniel S. Gardner and Allison Werner-Lin, 2012)

Role of Oncology Social Work in Medical Center

- Provide an introduction of cancer epidemiology, treatment, and the psychosocial, behavioral, and spiritual impact of the disease on individuals and families.
- Describe the history, conceptual foundations, and functions of oncology social work in general, and the field of psychosocial oncology.
- Describe the contributions of social work to oncology research.
- Define the scope of practice knowledge, skills, and interventions that oncology social workers use to assess and ameliorate psychosocial and quality of life concerns.
- Address emerging issues in psychosocial oncology including cancer survivorship, family decision making, genetic testing, and end-of-life care.
- Present selected resources available for patient education and support, and professional development (Daniel S. Gardner and Allison Werner-Lin, 2012).

Theoretical Frame Work

The purpose of this section is to present a theoretical frame work that can describe the socio-economic determinants on pediatric childhood cancer treatment adherence. Therefore, in order to explain the above-mentioned issue, the two theories are used (social capital and deprivation).

Social capital theory

Social capital is defined as the features of social organization such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit. The idea of social capital theory is that "not what you know, but who you know" determines one's economic, social, political, cultural position in the society. Hence one's family, friends, and associates constitute an important asset that can be called upon in a crisis. Conversely, the absence of social ties can have an equally important impact (Putnam 2000). A defining feature of being disadvantaged, moreover, is that one is not a member of or is even actively excluded from certain social networks and institutions that could be used to secure good jobs or decent work (Wilson 1996). Accordingly, social networks play an important role in mitigating the hazards of venerability and recovery of crisis.

According to Putnam (2000) social capital is classified into two categories: bonding and bridging social capital. Bonding social capital refers to all resources accrue by an individual by way of his/her relationship with family members and close friends. On the other hand, bridging social capital are resources that result from a person's loose relationship which are usually formed on a temporary basis for convenience purposes.

Social capital encompasses the other capitals (human, physical, natural and financial). For instance, when we relate social capital with human capital, human capital resides in individuals, social capital resides in relationships. Here this theory was selected due the fact that lack of social capital is one of the socio-economic constraints of pediatric childhood cancer treatment adherence. In addition to low family income and social attitude towards cancer the level of connectedness between children and their, friends, school, etc. have equal impact on the on the treatment adherence and curability. As Coleman (1988) this connectedness is a product of social relationships and social involvement that generates social capital. Coleman further suggests that the concept of social capital serves as a mechanism for transmitting the effects of family human capital from parent to children. For instance, those who endowed with a rich stock of social capital will be stronger to confront childhood cancer and take advantages of treatment adherence opportunities while one that from weak social networks and institutions fail to get access to treatment as a result could not get access of treatment and even if, start faced to abandonment of the treatment.

Deprivation theory

The deprivation theory refers to the idea that feelings of deprivation and discontent are related to a desired point of reference (i.e., reference groups). For example, relative deprivation theory is used to analyze the organizational issues of pay satisfaction. Relative deprivation theory focuses on feelings and actions. For instance, the theory encourages the exploration of an individual's feelings of deprivation that may result from comparing his or her situation with that of a referent person or group as well as the behavioral effects of deprivation feelings (Tropp 2004).

This theory also applies to individuals who find their own welfare to be inferior to that of others to whom they compare themselves (Nolan and Whelan 2007). According to deprivation theory, economic deprivation, social inequality and attitude towards social status are given emphasis to be causative factors of domestic venerability of social and physical hazards.

From another point of view, it is known that socio-economic status is often related to the social status or class of an individual with in or relative to a social group. Deprived individuals are also often powerless physically, legally and politically to extricate themselves from coercive exploitative labor, partly as a result of their social position (Cameroon and Newman 2008). According to this theory certain segments of society such as vulnerable groups in general and children with cancer and their family in particular may be deprived the opportunity to get access to comprehensive intervention due to socio-economic constraints.

CHAPTER THREE

3. Research Methods

3.1. Overview of the Study Area

The study was conducted at Pediatric Hematology/Oncology ward of Jimma Medical Center (JMC), Oromia Regional State, and South-West Ethiopia. I interested to study socioeconomic determinant of children's cancer treatment adherence which directly contribute to treatment abandonment. Because of treatment abandonment there is major challenge in the Oncology unit.

The above and interest to study the subject influence me to select the study area. Jimma Medical Center (JMC) is one of the oldest public hospitals in the country. It was established in 1930 E.C by Italian invaders for the service of their soldiers. JUMC is found in Jimma town, south west Ethiopia on an area of about 20,000 sq. meter. Currently it is the only referral center for critical and complicated health problems in south western part of the country, and providing service for 15,000 inpatients, 160,000 outpatient attendant, 11,000 emergency cases and 4500 deliveries in year from the catchment population of about 15 million people. It offers comprehensive health care service patients through specialty clinics and inpatient service departments. It gives services through four major departments (Internal medicine, surgery, pediatrics and Gynecology and obstetrics) and other minor departments are also available. Among the main inpatient service departments; Pediatric Hematology/Oncology Unit is the one which provides comprehensive specialized services to pediatric cancer patients. In this ward there are 20 beds with a total of 1 oncologist, 2 residents and 11 nurses and 2 porter and runners. In addition to that there are one social worker and counsellor those hired by other stakeholder.

On average, it gives services for around 150 childhood cancer patients per year. Generally, the Medical Center has 2000 staff and 800beds (J. M. C. O, 2020).

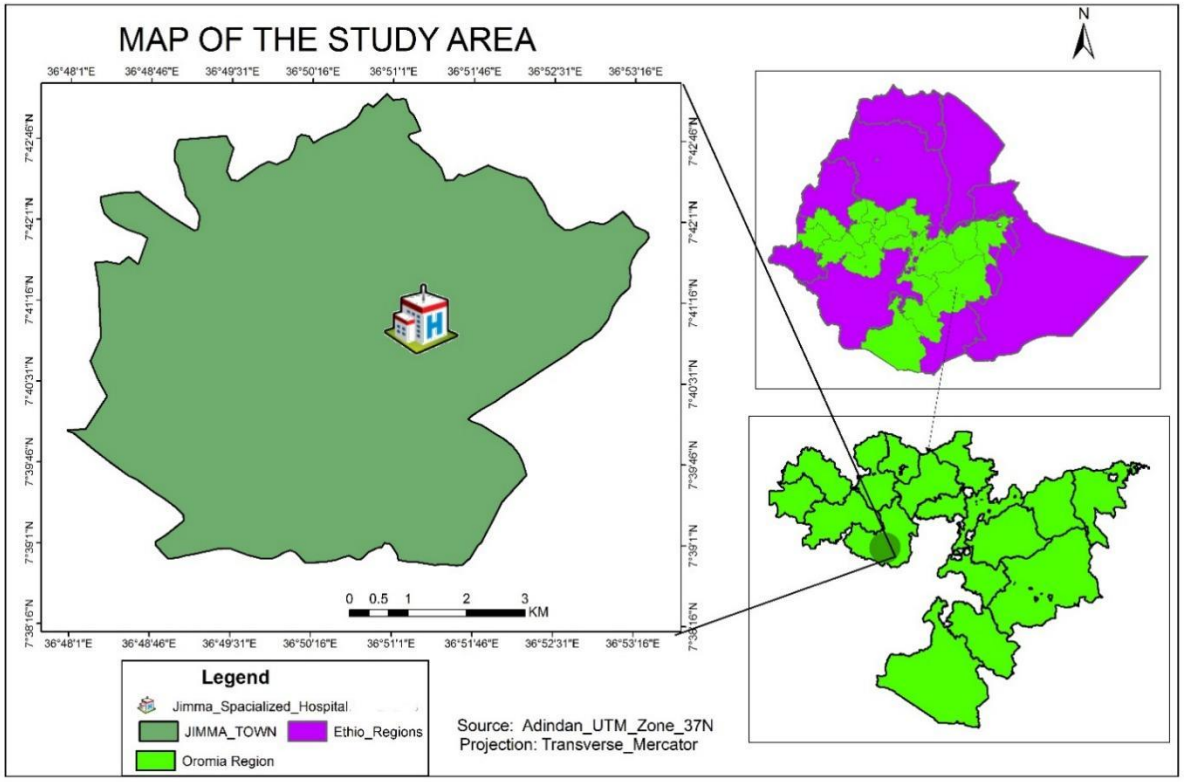

Figure 1: Geographic location of the study area (source: Madawe, 2019).

Research paradigm

The assumptions reflect a particular stance that I make when I choose qualitative research. After I make this choice, then further shapes my research by brining to the inquiry paradigms or worldviews. A paradigm or worldview is "a basic set of beliefs that guide action". Therefore, in this regard the I used constructivist paradigm which selected as a guiding framework for this study. This paradigm acknowledges that human beings have different understanding of reality and Subjective expression of the situation they are living in and it gives much emphasis for this individual explanation of the issues. Qualitative research begins with assumptions, a worldview, and the possible use of theoretical lens (Creswell, 2007). Among the existing four paradigms (post-positivism, constructivism, advocacy/participatory and pragmatism), I selected constructivism as best explaining the stance of doing this research. One

of the critical decisions that I need to make in designing my study is the paradigm (or paradigms) within which I situate my work.

So, based on these philosophical concepts I used constructive paradigms that suits to this kind of study because of I take into account the participants meanings and subjective interpretation on a Children's Cancer Treatment Adherence in the study area.

3.2. Research Approach

Method is a style of conducting a research work which is determined by the nature of the problem (Singh, 2006). I was conducted using qualitative approach since the research is exploratory. The qualitative approach fits with the research objectives and research questions. Qualitative research properly seeks answers to questions by examining various social settings and the individuals who inhabit these settings. Qualitative researchers, then are most interested in how humans arrange themselves and their settings and how inhabitants of these settings make Sense of their surroundings through symbols, rituals, social structures, social roles, and so forth (Berg 2001). For the reason that the study was about identifying how socioeconomic factors contribute to children's cancer treatment non-adherence; qualitative research was best suit for understanding the full picture of the non-adherence(abandonment) of treatment issues that exist among the study population(Berg, 2001).Qualitative approach was preferred because of its flexibility that allows me to review the overall research process.

3.3.Research Design

The purpose of utilizing a qualitative research enable to best illustrate, understand and grasp the human experience. Additionally, qualitative research helps to expand the scope of the individual experience and to discover more profound meanings within it (Creswell, 2009). Information was collected through detail interviews and observations in natural setting. Because

qualitative research tends to be exploratory in nature, the interviews of the participants was examined to reveal common trends and themes, which could then be interpreted and applied accordingly (Creswell, 2009). The study design was exploratory phenomenological case study to deeply explore and describe the impacts of socioeconomic determinants of children's cancer treatment adherence. The case study was very important in dealing with different events that the respondent experienced in their life and the case under the study was vital to investigate what events or experience that the care giver knows before and after start of support of pediatric oncology cancer treatment.

3.4. Sampling Technique

It is not expected to fear about the issue of representativeness in qualitative studies. Because, generalizing the finding is not the purpose of qualitative study. For this reason, I was selected the sample for the children's cancer treatment non-adherence until data saturation is reached. The sampling method selected for this study was non-probability sampling from which purposive sampling was specifically employed to select the participants (patient's family, doctors, nurses and administrative worker). As the main goal of purposive sampling is to focus on particular characteristics of a population (in this case cancer patient children's), it was best enabled me to answer basic research questions. Purposive sampling was employed to select doctors working in the oncology unit and cancer patient children's family because of the study was conducted with the intent to assess the impacts of socioeconomic determinant on the treatment outcomes of patients with cancer patient children. Purposive sampling is useful to study the characteristics of the participants' deeply, i.e., cancer patients, so as to reach the real persons to whom the issue of socioeconomic is more valuable.

3.5.Selection of study participants

As far as the sample size is concerned, the number of participants not decided as to be some number of persons. Rather it was determined by the persistence of the response of participants. The participants were selected from all segments of hospital that are believed to be part of the issue directly or indirectly. These segments are physicians, cancer patient children's family; hospital administrators, social worker and nurses whose participation believed to have an input for the study.

Sample size

There are patient's family with different background in the Medical Center and Medical Center staff. To address those family and staff member selecting participants purposively is very important. So, for the purpose of the study I was selected a total of sixteen (11) key informants. From those (5) five key informants were selected from the Medical Center Administration, and also three (3) from pediatric department. The reset (3) three are from pediatric oncology and non-government organization TAPCCO. Additionally, (5) five family of children with cancer to in-depth interview was included in the study to understand how they perceive the complex interplay of biological, socio-economic and treatment-related factors underlies this problem.

There were 14 participants from the family of patient's who participated in two FGDs. Each focus group discussion included seven members. I fix the number of samples to get sufficient and quality data from selected few.

Inclusion criteria and Exclusion criteria

Inclusion criteria

All families of children, those histopathological or cytological confirmed cases of childhood cancer below 18 years registered at Jimma Medical Center from 1st April, 2018 to 1st

May,2021 and had completed their diagnostic workup were included for the study. This is because of the time when full data of cancer patient children's starts to register in the unit. All Jimma medical center staff those have direct and indirect impact on the pediatric oncology unit client's and other stakeholders

Exclusion criteria

Those with incomplete workup, previous diagnosis of cancer and who received any cancer directed treatment at other institute were excluded from the study. Diagnostic criteria were specific for different cancers as per institutional protocol.

3.6.Data Collection Instruments and Procedures

3.6.1. Source of Data

Data was triangulated by combining data from different sources for broader and deeper understanding of the research issue. I was employed both primary and secondary sources of data. The primary source was mainly included empirical data to be gathered from the patient, family, doctors, nurse, social worker and administration staff of the hospital and nongovernmental organization staffs. To substantiate the primary data, I reviewed secondary sources like documents from government and non-governmental organizations, those have information and medical records of clients.

3.6.2. Methods of Data Collection

To answer the basic research questions, I conducted semi-structured interview with patient family, and professional in the unit and in medical center arrange Focus Group Discussion (FGDs) with different groups from the patient family, make observation in oncology unit and revisit different documents and reports.

Semi-Structured Interview was the main method of data collection. Kalewongel (As cited

in Girma. E, 2016) indicate that in-depth interview with selected individual enable me to gain insights about people`s opinion, feelings, emotions and experiences in detail. Semi-structured interviews contain both pre-planned and unplanned questions which can clear link the questions with the research question and help me to probe the respondent for further clarifications. Focus Group Discussion (FGDs) is the second method by which I was collected data. FGDs was done with family of cancer patient children and important to understand the factors contributing to children's cancer treatment (non-adherence) abandonment. Also, I was used phone call interview to gather data from those abandoned patient family and far from JUMC and difficult to travel. This is done by taking their phone number from medical records which recorded by TPCCO, NGO social worker to fellow up. In addition, observation was also made to see the feeling, emotion and action that occurs among the study population.

Finally, documents and literature review were employed to support primary data by secondary sources that was gained from reports, medical records and other organizations documents. During semi-structured interview I combined both taping and note taking to gather information. The semi-structured interview and Focus Group Discussion (FGDs) was conducted in Afaan Oromo and Amharic language.

3.6.3. Data Collection Instruments

I was used different methods of information eliciting tools. These include observation checklist, semi-structured interview guide (for in-depth interview) and key informant interview guide FGD guide line, document review checklist.

a. Interview Guide line

A semi structured interview guide was used to get information from the family of cancer patient children. The interview for family was prepared in English and present to them by me being translate into Amharic and Afaan Oromo languages. I used a topic guide that serves as a checklist to ensure that all respondents provide information on the same topics. There was an open window for me to probe areas based on the respondent's answers or ask supplementary questions for clarification.

b. Observation Check List

This tool was used to collected data on a natural setting through visiting the medical center (oncology), observing the interaction between the patient and the doctor and the nurse during their stay in the medical center**.** Checklist was prepared which guides the data collection process. Since I'm practically experiencing the issue as indicated above, it is very interesting to conduct the study through observation which enriched the study with a practical input. I classified the observation into two parts/aspects. The first one was concerned with the physical infrastructure/physical environment which includes as treatment room, registration/card room, toilet, bedrooms, laboratory and pharmacy.

The second area/aspect of observation focused on observing the treatment process. This was the most important part of the research. I was collected data through non-participant observation on the treatment process using observation checklists. The checklist includes doctor's interpersonal skills, discipline/respecting the patient, decision making process, counseling (issues or topics of counseling like prescription, life style modification), knowledge of language/culture of the patient on the side of doctor, the patients' sense of freedom to present

their issues freely/clearly**,** over all communication environment (enough time, patient freedom, doctor's welcoming face/smile, sense of status difference-superior inferior, who speaks more and the use of medical terminologies).

c. Key informant interview Guide Line

This was conducted on participants identified by the researcher to be a key. These was with administrators, medical director (nurse head and JUMCCO. These participants provided insight on the nature of problems and give recommendations for solutions.

d. Focus Group Discussion Guide Line

I was conducted focus group discussion as part of a series in which the participants vary but the area of interest is consistent and permit alternative ways of participants. To used its advantages like flexibility of design, actionable insight into participant knowledge and straightforward way to gather accurate data etc. FGD was conducted with cancer patient children's family those come from different place and social back ground. I was conducted two FGD session and in each the group seven parent participated. One FGD was completed in forty-five minutes up to one hours. During FGD the moderator facilitated and take note.

3.7. Methods of Data Analysis

Depending on the nature of the study, data was analyzed by using thematic analysis. This was done in order to create stories which was emerge from experiences of the participant. Each interview with the research participants was audio recorded and the recorded sound was transcribed by taking key points from the interview. The data analysis was beginning in categorizing and putting data into theme-the data with regards to economic and social patient and

their family. I used exploratory analysis method because it was useful to explore the conversation done during the interview and discussion by, me with research participants.

In addition, based on the classification of data with regard to the challenges and opportunities of the subject under study, I was interpreted and put the data in the form of statements and arguments. Furthermore, the data obtained from different documents was interpreted in the form of narration. The data gained through Focus Group Discussion and Semi-structured interview was discussed and analyzed on how the participants experience on the phenomena under study. Finally, what I experience during personal observation was analytically written in line with the theme that is going to be formed.

3.8.Ethical Consideration

Considering ethical issue during any research issue is important. For this study, Voluntary consent was first issued to consider. I was allowed individual to partake in research according to their own free will and I informed participants that the research is voluntary and that they can withdraw at any time. Informed consent on which participation in the research as well as the recording of the interviews was taken place with the participant's informed consent is the second ethical issue to be considered. Thirdly, confidentiality was kept on which I not and cannot identified the participant and I can have matched names with responses, but ensure that no one else was have access to the identity of the participants was be crucial.

3.9. Trustworthiness of the Data

Phenomenologists have coined the term bracketing to describe the process of becoming aware of one's implicit assumptions and predispositions and setting them aside to avoid having them unduly influence the research (Husserl, 1931). This process assumes that it is possible to fully know oneself and one's presuppositions, which some would argue is impossible. However,

qualitative researchers use particular strategies to unearth their previously unacknowledged assumptions. It is important to note that many factors may interfere with a fair collection and interpretation of data, including the researcher's emotional involvement with the topic of interest, presuppositions formed from reading the literature, and various aspects of interaction with research participants, (Husserl, 1931). Suitability of the data abstraction format was assessed through in-depth discussion with experienced oncologists and research advisors. In addition to that trustworthy of the study was enhanced by having good rapport with participants and engaging in field during data collection time. And pretest was also done on 5(five) patient's family who were admitted to Pediatric Hematology/Oncology ward of JMC to ensure consistency of data collection format and appropriate modifications were made accordingly. The principal investigator together with the trained data collectors was responsible to review and update all patient data needed for the identification of socioeconomic determinant contributes on a daily basis. The principal investigator was also responsible for on spot supervision of the work of the data collectors.

CHAPTER FOUR

4. Data Presentation and Analysis

This chapter includes a review of pertinent literature different, different concepts explored based on thematic classification of finding from the information's by focusing on their experiences with perceptions of socioeconomic determinants on childhood cancer treatment adherence in pediatric oncology unit.

Data gathered through non-participant observation, key informant interview, in depth interview, and focus group discussion. The thematic classification of informant's ideas helped me to conduct effective analysis of finding. In health care service organizations professional workers named as health care providers, physicians and nurses they provide medical treatment, and nursing care based on their educational level and experience. I used these terms interchangeably in analyzing the information obtained from different sources.

According to the data collection time schedule I observed different actions of health care providers and patients. The data obtained from the Jimma Medical Center Administration the medical center offers comprehensive health care service patients through specialty clinics and inpatient service departments. It gives services through four major departments (Internal medicine, surgery, pediatrics and Gynecology and obstetrics) and other minor departments are also available. Among the main inpatient service departments; Pediatric Hematology/Oncology Unit is the one which were purposively selected. In this unit there were different patient and patient attendant which come from different parts of the country spatially southwest part. There were also different health care providers in the word to serve clients / patients having different socioeconomic status and cultural background. I observed the unit and gathered necessary information were collected by taking notes what is going in each part of the unit concerning the

study objective. Based on the specific objective of thesis the following finding were generated and presented with a thematic classification of informant's idea in terms descriptions and explanations

4.1. Socio- Dimorphic Characteristics of the Research Participants

Table: 4.1 Background information of key informant interview participants

Participant's code	Sex	Age	Educational background	Role and responsibility	Work experience	Work place
HW1	M	39	Medical Doctor	CEO of the Medical center	15	Jimma Medical center
HW2	M	40	Oncologist (PhD)	Unit head and clinician	17	Jimma Medical center
HW3	F	32	Nurse	Social worker	10	Jimma Medical center
HW4	M	37	Sociology	Social worker	12	TAPCCO
HW5	F	28	Social work	Counselor	3	TAPCCO
HW6	M	37	Nurse	Oncology nurse Unit head	10	Jimma Medical center
HW7	F	45	Pharmacist	Oncology pharmacy head	18	Jimma Medical center
HW8	F	32	Nurse	Nurse	8	Jimma Medical center
HW9	F	27	Nurse	Nurse	3	Jimma Medical center
HW10	M	37	Pharmacist	Chemist & Dispenser	11	Jimma Medical center
HW11	M	36	C. oncology Nurse	Nurse	11	Jimma Medical center
HW12	F	30	Nurse	Nurse	5	Jimma Medical center
HW13	M	36	Pharmacist	Druggist	9	Jimma Medical center
HW14	M	33	Medical doctor	Resident	2	Jimma Medical center

Table 4.2.2 In-depth interview participants' profile

Participant's code	Sex	Age	Educational background	Role and responsibility
CP1	M	38	Diploma	Household head
CP2	F	35	Illiterate	Household head
CP 3	M	Date	Grade 3	Household head

Table4.2.3: Focus Group discussion (FGD) participants

Participant's code	Sex		Number of participants	Discussion hours	Date	Discussion place
	Male	Female				
GR 1	3	4	7	1: 07 hour	May30,2021	Jimma medical center oncology play room
GR2	5	2	7	00: 58 Minute	May39,2021	Jimma medical center oncology play room

4.2. Socio-economic Determinants and its Impact on the Pediatric Cancer Treatment Adherence

Since the major aim of this study is to assess socio-economic determents impact on the pediatric cancer treatment adherence at Jimma Medical Center I collected information on knowhow of different health care providers and patients/clients about socioeconomic determinants how they define and give meaning and relate treatment and treatment adherence using key informant interview, in-depth interview and FGD.

Overall data collection of the started by observing the medical cancer and specifically pediatric unit. During the observation time different patients were at the clinical and diagnosis room. I met clinical director at medical center who is medical doctor. We

exchanged greeting and I introduced myself with full of information what I want from the hospital administration regarding the study. I raised a simple question about the meaning of socioeconomic determinants, how relate with treatment and impact on treatment adherence on specifically pediatric cancer treatment.

Based on prior knowledge of HW2, the participant provided simple definition for cancer and treatment adherence, then go to the impact of socioeconomic determinants on pediatric treatment adherence.

> The most basic terms, cancer refers to cells that grow out-of-control and invade other tissues. Cells may become cancerous due to the accumulation of defects, or mutations, in their DNA'' and treatment adherence as "patients actively participate in their treatment plans and take their treatments as recommended by their healthcare providers.

According to HW2 typical problems of the children with cancer and their family are:

> "The medical center is far from the community and most of the patients and relatives challenged with transportation and its cost; medial and accommodation expense; COVID-19 pandemic and its socio-economic challenge; hinder the clients to access treatment and adhere to treatment guideline."

From clinical nurse and pharmacists those participate as key informant they just rise childhood cancer: "*As the duplication of abnormal cell and its cause is unknown. And also, if early diagnosed and get compressive intervention (treatment) it's curable*".

Then they raised issue of the impact of socioeconomic determinant on the childhood cancer treatment adherence.

Socioeconomic Determinants of Treatment Adherence

> "Most children come to the medical center are from low socio-economic status and low awareness about chronic diseases and due to this the families or guardians of vulnerable children to cancer don't adhere to treatment. The other challenge is for those come from furthest rural area of south west part of the country by itself is a challenge, they don't know modern life and they can't afford the living cost and medical expense. Hence, many children interrupt treatment and come back to hospital when the illness worsen and the stage become sever. That make many clients (patient) to non-adherence treatment."

HW5 raised as cancer as;

> As it's a chronic disease which need holistic intervention and want community-based intervention. Social and economic determinants are back bone to the success of any intervention that means socioeconomic determinants has an impact on the childhood treatment adherence.

Focus group (GR1), discussion conducted with family/ attendant of children with cancer revealed that attendant gave their reflection regarding the impact of socioeconomic determinants on the childhood cancer treatment adherence.

> The social system which we live has a countable impact on over all of our life and specifically the treatment our of children's. The society were we from are not have an understanding about childhood cancer and the treatment of childhood cancer, even if can't now the child can face cancer accept a few. This makes them to feel and rise idea like not to send children with cancer to treatment center, rather than that they advise and sometime comment on us to why we not fellow spiritual and traditional treatment like Ruqa and Tebal and other traditional treatment. The other is most of our community member think as making both medical and other one is no appropriate. This and other

things make them not supportive to as many times and to feel on us when come to hospital search our comfort not to the treatment of children. In addition to the above the conflict, chaos in society is other major challenge them on attending the treatment appointment date which enforce them to treatment non-adherence.

Additionally, family of children with cancer those participated to in-depth interview was put their perception to the complex interplay of biological, socio-economic and treatment-related factors underlies this problem. As the childhood cancer treatment of their children are affected by social and economic status of themselves.

CP1 says when he reflects his understanding on the impact of socioeconomic determinants on the adherence.

"Rakkochi rakkoo ulfaatadha an qebeenya qaba jedhee namni tokko kophaa isaa baadhachuu dandhu miti, haa tahu male akkuma loomiin shatamni nama tokkoof ba'aa nama shantamaaf immoo faaya jedhamu kunis akkas tahuu qaba jedha"

This means the problem is so difficult to handle even if he/she is reach, but as fifty lemon is difficult lode for one person but for fifty person it is luxury. Due to this childhood cancer treatment need support from community, humanitarian organization and government institution.

4.3. Importance of Supportive Socioeconomic Condition to Treatment Adherence

4.3.1. Health Care Providers View on the Importance of Supportive Socioeconomic Condition Treatment Adherence

I raise question to the medical center administration (CO) on the importance of supportive socioeconomic condition and what it look like in the medical center. He says:

Hundred percent it's important to deliver congruent service and treatment to client. When we come to what it looks like in our medical center, we have recently opened social work

unit by making attention to the social part of intervention and make our intervention holistic and increase curability rate.

HW2. Say:

"As the poor or not supportive socioeconomic condition is major challenge to the successful treatment and enforce to treatment non-adherence and reduce the curability rate, active and supportive socioeconomic condition essential in the process of comprehensive treatment innervation for level up the curability rate. In case of Jimma Medical Center there is good beginning both by social and economic support for all needs in the medical center but it's still at infant stage which want many jobs improve. So that there is no question on the importance of supportive socioeconomic condition."

In the same manner I raised similar question to other health care providers the same to HW2 all of the informants rise by putting high attention on the issue of social and economic role to enhance childhood cancer treatment adherence that led to improve curability rate of childhood cancer patients. From health care provider HW4 say: "*There is not complete treatment not only complete treatment and also successful treatment without supportive socioeconomic condition*".

The other also rise as all concerned individual, group, institution and any one must put his/ her effort to social and economic condition that support health system and person with health problems.

The HW10 participant from health care providers say:

Poor approach to client and financial problems of client family major challenges which commonly seen in this unit even if tried by this medical center, non-government organization and a person who have good heart to support those vulnerable children and their family still their huge action gap.

.

4.3.2. Parents View on the Importance of Supportive Socioeconomic Condition to Treatment Adherence

Data gathered from focus discussion GR2 parents showed that:

> "Supportive socioeconomic condition important to fill up shortage of medical and social care deliver for their children which is input for the success of treatment adherence. And increase curability of children with childhood cancer as childhood cancer need multidimensional intervention due its complexly in addition to that reduce misunderstanding among health care providers and client as result of social and economic problems that faced the client in medical center occur during intervention time."

CP3 revealed that:

> The fact socioeconomic determinants should gate attention and everyone from individual to higher organization contribute to those in need to get their health back this by done by reducing client socioeconomic problems and empowering them which led the client to treatment adherence.

4.4. Barriers to Treatment Adherence in Jimma Medical Center Pediatric Oncology

4.4.1. Social Barriers to Treatment Adherence in Jimma medical Center Pediatric Oncology

From key informant HW2 informed that:

> Sometime social pressure had escalated to such an extent, that the child's parents had already abandoned treatment. For instance, in the medical center different health care providers from different area of the county joined to serve client who

> has different social background, but most of them are not have training or they are not clinical oncologist they just working by their general clinical nurse knowledge this challenge those health care providers to provide culturally appropriate this a huge berries to service delivery by developing misunderstanding and imposing distrust between service providers and family of children with cancer.
>
> For, example during conversation sometimes misunderstanding between health care service providers and patients would happen. These results the health care disparities.

The other health care provider informants revealed that inability to communicate with a client and not knowing social background of client create a barrier to accessing health care and also undermines trust in the quality of medical care received and decreases the likelihood of appropriate which directly contribute to treatment non-adherence.

It was pointed out by HW6 of the study participants that:

> Cancer patient's family and their relatives had negative attitude towards cancer treatment modalities, particularly for chemotherapy. They believed that chemotherapy damages the internal organs of the human body.

One of the respondents astonishingly mentioned that:

> "Cancer patients believe that chemotherapy burns human body. They thought that a person treated with chemo end up with death. When they consult the family or neighbors whether to take a prescribed chemotherapy or not, they were not encouraged to go to the treatment center and take the treatment regimen. Consequently, it is with dread that they come to the treatment center"

In depth interview participant CP2 point out that:

Medical treatment is based on the history of patients at health setting through dialogue and conversation conducted during clinical diagnosis. During the process to getting clinical service patient / client/ confront serious social barriers like language, place in the medical center where to start the process facing new persons with different personality and social background

4.4.2 Economic Berries to Treatment Adherence in Jimma Medical Center Pediatric Oncology

Patient's /client/ came to the hospital selling their family assets such as livestock and even home to cover the trip and treatment costs even though there is no assurance of cure. This puts the family in desperate situation. According to the HW9 respondents:

> The service cost at JMC is fair since the service is subsidized by the Medical Center. And even for patients who can bring official letter from their local administrative unit permitting free service, the hospital gives the service free of charge.

. HW2 emphasized on:

> "People go home to die since there is a chronic chemotherapy drugs shortage because of the imbalance between supply and demand. When patients want to buy the drugs from private pharmacies, the cost is totally unaffordable and sometimes the private pharmacies unacceptably increase the cost of the drugs if they know that the drugs are not available at the JMC''.

4.5 Traditional Practice of Client as Barrier to Treatment Adherence in pediatric Oncology

The response from HW3 showed that traditional religious practice become serious health care service barrier.

*"*Different patients before coming to health care service organization they used traditional medicinal plants through indigenous healers which was not scientifically tested. When they come to the hospital the condition of treatment would result as severe problems which is reduce the curability of the client. If the curability change is rare, non-adherence of the treatment is high by losing hope on the treatment."

As HW8 response revealed that *"client think that using traditional medicine at local environment can reduce the cost they incurred for transportation from their local to medical center fees and time consumed during diagnosis".*

4.6 Workforce Employment and Childhood Cancer Treatment Adherence

Regarding workforce employment in the medical center oncology HW6 told me that

*"*During employment of new health care provider, the criteria for recruitment and selection are educational level and work experience. There are no other criteria that considers childhood cancer treatment issues. After employed there is no special training no issues of knowledge about the client's background, norms, belief, values and health care service providers-client communication which related with childhood cancer treatment as the case of cancer need special intervention"

Finding from the focus group discussion GR1 revealed that health care service provider in pediatric oncology must be improve their understanding regarding culture of society they serve and working environment. Culture elements like the language, the belief, the customs, values and norms must be recognized by employee.

4.7 Training Concerning Pediatric Cancer Treatment and Infrastructure in the Pediatric Oncology

Regarding workforce employment and empowering in the medical center oncology unit HW2 told me that:

> "There is no training regarding childhood cancer treatment and client approaching psychosocial support, on this chemo preparation and other issues. This area knowledge and understanding every important to the successful treatment and enhance treatment adherence. Also we can't have outpatient to those have fellow up and come based on their appointment"

HW11 revealed that *"there is no training on important topic to deliver full treatment which increase curability and treatment adherence*" and HW12 shown that "*there is delaying of repairing equipment like chemo preparation machine, due to this we are preparing chemo on open space by taking risk*".

Chapter Five

5. Discussion

Data were analyzed along specific objectives of the study based on literatures collected from publication and unpublished sources. The main findings regarding the analysis of the association socioeconomic or the various components of socioeconomic and adherence were as follows, income, level of education, and employment/occupational status were significantly and absolutely associated with the level of pediatric oncology adherence.

Finding from all informants regarding the importance of supportive socioeconomic condition showed that supportive social and economic condition in medical center helps health care providers for effective and congruent medical practice in the medical center which contribute treatment adherence of childhood cancer patients. Understanding and participating in supportive social and economic condition to health care service institution and agent to create conducive environment for clinical diagnosis and treatment adherence Economic factors such as poverty, unemployment and lack of food were consistently mentioned by participants in relation to the question about their experiences on childhood cancer treatment.

In medical setting, effective communication between clinicians, patients, family and other health care provider is fundamental. A main tenet of anthropology is social aspect of society is the most important because it is the primary way a social background understands. This notion holds true in health care setting. The socioeconomic determinants are most powerful in childhood cancer treatment intervention (Woloshin et al., 1995).

Most participants were from rural framer and experienced poverty as a result of this. The lack of income and expensiveness medicine meant that most of them were unable to buy food or afford transportation costs to meet their treatment appointment dates. The prolonged and expensive

treatment of childhood cancer cannot be afforded. Poor socio-economic status therefore must be seen as a poor prognostic factor in childhood cancer. Keep in mind that when a child has cancer, its family generally falls into a lower socio-economic class as treatment is expensive and parents are not able to keep their job or social position. Subsequently substantially fewer children with cancer in the developing world achieve cure or long-term survival.

process and challenge enforce parents to treatment non-adherence social like mis-Finding from those participated in in-depth interview revealed that functional socioeconomic determinant solves non-congruent treatment understanding about cancer. Its cracks poor community support to the vulnerable family to this health problem by keeping his/her compound and supporting the rest family up to they come back and economic problems.

This study showed that traditional beliefs and practices had strong influences on people's ability to adhere to pediatric childhood cancer treatment. This finding is consistent with that of Peltzer et al., 2011) which suggests that the use of alternative medicines was gaining popularity globally and may influence more patients to be non-adherent to treatment in the future. Health education to patients should include an awareness of the interactions that traditional medicines may have on patients on pediatric childhood cancer treatment, and health workers should be sensitized to include this in adherence support and counseling.

The essential of focus of childhood cancer treatment training in the health professions is on the care giving relationship between health care providers and clients on how services delivered to diverse client populations.

Nearly all participants argue that technical solutions are 'just one part of the puzzle psychosocial issues must be addressed as well. The main hurdles to adherence remain financial and humanistic in nature. Many more factors are involved in adherence: health care providers,

systems of care, treatment modalities, social environment and so on. Asking about adherence in a non-threatening manner and monitoring it should be universally adopted and reflects good health care. Adherence can be improved by discussing possible treatment choices with the patient and the logic behind them. It is more often the socioeconomic variables which will ultimately determine lasting change. Finding shows the unit is still in immaturity stage in which there are not enough social and economic support to deliver sufficient service.

The finding on the empowering and updating on the area intervention there not sufficient training and workshop to health care service providers, it is important that administrators at medical center and health care policy makers must aware of their advantage of recognizing the positive implication of training to secure the knowledge base and procedures necessary to fulfill the intention of laws regarding the clients served at different health care service centers.

The finding from the study regarding traditional practice also implied that clients at their local environment used cultural medicine trough indigenous healers. The case of clients become complex and challenge during clinical treatment session due to traditional practices of client before coming to the medical center this directly contribute the non-adherence of treatment.

The service cost at Jimma Medical Center is fair since the service is subsidized by the Medical Center. And even for patients who can bring official letter from their local administrative unit permitting free service, the hospital gives the service free of charge. However, the study participants reported that the service is not persistently available at the hospital and sometimes there is interruption.

The finding of study consistent with the finding of (Kebede, Alemayehu, Binyam & Yunis, 2014). Religious practices play a large part in the healing process for Ethiopians such as praying

tsalot and going to church and by Moslems side ***ruqa.*** Holy water for Orthodox Christians (called '***tsebel***' in Amharic) or '***zemzem***' in the case of Moslems is also frequently used for a wide variety of illnesses. Ethiopians believe that holy water cures when it is drunk or bathed it.

Treatment adherence should be treated as more than just a medical issue. It involves social, political, financial, and environmental considerations that may often be outside the control of the patients or their families. It is not only just related to the direct expenditures associated with the treatment, but also indirect costs, such as decreased income, as many parents become unemployed looking after the sick child (Mostert S, Gunawan S, Wolters E, et al.2012).

The finding of this study similar with the study done by Ishaya and Adahin (2016) regarding role of socioeconomic factors in abandonment of cancer treatment among pediatric patients in Jos Nigeria, tries to determine the association between socioeconomic factors and abandonment of pediatric patient treatment. As there finding in 2016, they get 63.4% of prevalence of abandonment which observed in developing country and identified major cause to abandonment as socioeconomic, parental occupation and maternal education (Ishaya & Adah 2016).

Chapter Six

6. Conclusions and Recommendations

6.1 Conclusions

The medical center is far from the community and most of the patients and relatives challenged with transportation and its cost, medial and accommodation expense, even if some expense and one line transportation cost covered by Tasfa Addis Parent Childhood Cancer Organization (TAPCCO), The other is COVID-19 pandemic and its socio-economic challenge, hinder the clients to access treatment and adhere to treatment guideline. The prolonged and expensive treatment of childhood cancer cannot be afforded. Poor socio-economic status must be seen as a poor prognostic factor in childhood cancer. Keep in mind that when a child has cancer, its family generally falls into a lower socio-economic class as treatment is expensive and parents are not able to keep their job or social position. Non-adherence influenced the prognosis of childhood cancer, and was associated with cultural and local perceptions of cancer and the economic power of the affected families. Prevention of abandonment is a prerequisite for successful cancer care, and a crucial early step in quality improvements to care for all children with cancer which is important to increase the curability rate pediatric childhood cancer.

Participating to correct challenges of socioeconomic determinant, solves non-congruent treatment process and challenge enforce parents to treatment non-adherence. Its cracks poor community support to those vulnerable family to this health problem by keeping his/her compound and supporting the rest family up to they come back and economic problems. The majority of cases who started chemotherapy didn’t complete all the treatment cycles because of shortages and absence of safe and affordable chemotherapy drugs and social and economic problems faced them during treatment process.

6.2. Recommendations

Based on the finding of the study the following important recommendation are forwarded for the respective body on pediatric childhood cancer treatment, treatment program implementers, policy makers and researchers who are engaged in this area:

The government and the hospital should give emphasis to establish cancer therapy centers and insure accessibility and affordability of chemotherapy drugs.

Create programs to increase the community knowledge about childhood cancer and early treatment methods of pediatric oncology cancer.

Health care providers should give special attention for early symptoms, consult, and give immediate response to the patients for early diagnosis of pediatric cancer screening.

Finally, better studies are needed as well. Investigators should make use of standardized definitions of adherence and reliable measurement instruments, one should conduct more multidisciplinary studies and well conducted qualitative studies for a better understanding of adherence.

As childhood cancer treatment intervention need holistic or comprehensive intervention and done by the case management team, social worker has major role in the overall case management cycle to due to that medical center social work unit should prepare training to the staff and work closely with Jimma University School of Social Work.

Jimma University School of Social Work as it’s producing competent and strong social worker those stand to disadvantage group and manage complex social problems should give attention to the problems exists in medical center in general and pediatric oncology unity particularly.

Implications for Social Policy

As increasing consideration is being paid to the important ways that care coordination and team-based care can improve the quality of care for patients in the community (Grumbach & Bodenheimer, 2004; Institute of Medicine, 2008; Saba, Villela, Chen, Hammer, & Bodenheimer, 2012), support for further pediatric childhood cancer patient based medical settings will likely grow as well.

Nowadays the issue of improved public health is getting more attention both from the government and the community. The issue of pediatric oncology treatment adherence is the most important thing to increase curability rate of children with cancer. Hence it is better if the government pays attention and assign budget, just like other areas of health, to deal with pediatric childhood cancer treatment adherence aspects of health. The treatment adherence aspects of health are as important as the others aspects. All social problems associated with illness can be dealt by treatment adherence effectively than the medical practitioners who believe that they can deal with all aspects of a patient but fail to see and deal with other issues except the biological implications of a disease

Implications for Social Work

The social work profession promotes social change, problem solving in human relationships and the empowerments and liberation of people to enhance wellbeing utilizing theories of human behavior and social systems, social work intervene at the points where people interact with their environment principles of human rights and justice are fundamental to social work (IASSW/IFSW ,2001). National association of social work in 2001 described that social work utilizes a variety of skills, techniques, and activities consistent with its holistic focuses on persons and their environments. Social work interventions include counseling, clinical social

work, group work, family treatment and therapy as well as efforts to help people obtain services and resources in the community. People who seek medical treatment need guidance beyond the actual identification and treatment of a medical problem (Volland, 1996).

The rationale for social work involvement in pediatric oncology medical services is straightforward. Pediatric childhood cancer treatment is an important area of intervention for social work. Poor treatment adherence is posing any impact both on the patient and family and then affects the general society. The pattern of the relationship determines the whole process of treatment and finally it may cause the ultimate goal of medical practice left unmet. If client non-adhere to the treatment, the treatment fail. This condition prevents patients from achieving improved physical and emotional wellbeing finely the result may not good. Social work has great contributions to improve treatment adherence. The improvement in treatment adherence has important role to the achievement of better health among the patients. Due to the fact that better good patient interaction has positive relationship with patient adherence to medical treatments and improved health outcomes. Social workers assist patients with chronic illness in navigating the complex healthcare system, explaining treatment options, deal with social or environmental problems associated with the illness, modifying behavior and finally attaining optimal level of social, psychological and physical wellbeing. Hence social workers play various roles in the medical setting including patient/problem assessment, developing intervention/treatment plan, identifying and dealing social and psychological barriers, counseling patients modify their social environment and educating patients about preventive care and self-care (chronic illness management)

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Annex I

I. Consent Form

Jimma University College of Social Science School of Social Work

The socio-economic determinants of children's cancer treatment adherence; the case of Jimma university medical center**.**

Greeting: Hello, my name is_____. I am here today to collect data on the Socio-economic determinants of children's cancer treatment adherence; the case of Jimma university medical center. The study is being conducted by Mr. Abdulmalik Zakiyu from Jimma University College of Social Science, School of Social Work post graduate program.

The objective of this study is:

- ✓ To identify the social economic factors challenges in offering children's cancer treatment in the oncology unit.
- ✓ Economic factors challenge in offering children's cancer treatment in the oncology unit.
- ✓ To know the effect of economic factors on children's cancer treatment adherence
- ✓ To find out the influence of social factors on children's treatment adherence
- ✓ To know the impact of family size on children's treatment adherence.

This is an exploratory research approach to explore and describe the impacts of socioeconomic determinants of children's cancer treatment adherence, so that I request you to take part in this study. Your cooperation and willingness is greatly helpful in assessing the impacts of socioeconomic determinants of children's cancer treatment adherence in Jimma University Medical Center.

Your child name will not be written in this form and will never be used in connection with any information we take from you tell us. There is no possible risk associated with participating in this study except the time spent to deliver information for us.

All information given by you will be kept strictly confidential. Your participation is voluntary and you are not obligated to participate in the study.

If you feel discomfort with the study, it is your right to drop out the study. If you have questions regarding this study, please feel free to contact me.

Address of the researcher:

Abdulmalik Zakiyu

Cell phone: +251- 934292724

E-mail: zzamalik2018abdul@gmail.com

Are you willing to participate your child in this study?

1. Yes - ……. Continue

2. No - …… Skip to the next participant

Appendix 2: Key Informant Interview (Administration Office)

Jimma University College of Social Sciences School of Social Work

Title: The Socio-Economic Determinants of Children's Cancer Treatment Adherence;

The Case of Jimma University Medical Center.

My name is Abdulmalik Zakiyu, a student at Jimma University School of Social Work, attending my education in Masters of Social Work. I am conducting a research on the title **"An** assessment of the socio-economic factors contributing to children cancer treatment adherence. The Jimma Medical Center, Oromia region state Ethiopia. The objective of this study to assess the socio-economic factors contributing to children cancer treatment adherence. Dear interviewee you are selected to provide information that will help achieve the above-mentioned objective of the study. I do not need to know your name. With your permission; I wish to ask you the following questions. Please respond as frankly and honestly as possible. Thank you in advance for your time and cooperation.

I. Background of the Key Informants

Position/work: _____ Date of interview_____

Address _____ Place of interview _____ Duration of interview_____

1. How many workers does the hospital have? Technical _____ Administrative _____ Total _____
2. How many departments are found in this hospital? _____
3. Is it pediatric oncology unit is one of the departments in the hospital?

What is the annual budget of the hospital and specifically pediatric unit? _____

4. How many patients are expected to diagnose per a day? _____
5. Do you think that the physical infrastructure (bed rooms, treatment rooms, materials, pharmacy and others) of the hospital is good enough in all aspects in order to provide a good service?

   If no, what impacts did this case is posing to the treatment service provision?

   _____

   _____

6. How many doctors and nurses are working in the pediatric oncology unit? _____
    - Do you think that this number is sufficient for providing a good service which promote treatment adherence?

    If no, what impacts did this case is posing to the treatment service provision to childhood cancer client?

    _____

    _____

    - How do you see the health care system would looks like for childhood cancer client, on the issue of treatment expenses and service delivered?
7. Is it sufficient physical infrastructure for pediatric oncology unit to deliver service for client?

    If no, what is it's the impact on service provision of service and what should be done?

    _____

    _____

    - What should done to enhance treatment adherence of pediatric oncology patients (client)

      _____

    - 8. Finally please state other comments you have.

      _____

    _____

    _____

Thank you very much for your cooperation!!

Appendix 3: Key Informant Interview (pediatric oncology unit staff)

Jimma University College of Social Sciences School of Social Work

Title: The Socio-Economic Determinants of Children's Cancer Treatment Adherence; The Case of Jimma University Medical Center.

My name is Abdulmalik Zakiyu , a student at Jmma University School of Social Work , attending my education in Masters of Social Work. I am conducting a research on the title **"An** assessment of the socio economic factors contributing to children cancer treatment adherence. The Jimma Medical Center, Oromia region state Ethiopia. The objective of this study to assess the socio economic factors contributing to children cancer treatment adherence. Dear interviewee you are selected to provide information that will help achieve the above mentioned objective of the study. I do not need to know your name. With your permission; I wish to ask you the following questions. Please respond as frankly and honestly as possible. Thank you in advance for your time and cooperation.

I. Background of the Key Informants

Position/work: _____ Date of interview_____

Address _____ Place of interview _____ Duration of interview_____

II. Guiding Questions for Key Informant (With 4 participants)

1. For how long you know the unit and children diagnosed the children's cancer?
    - What kind of position or work do you have?
2. What are the major challenges that children diagnosed to childhood cancer encounter during treatment in the study area?

- What do you think about the social factors impacted on children's with childhood cancer client and their family? And also on the childhood cancer treatment
- How do you perceive children with childhood cancer? How often do you interact with children?
- Could you tell me about your experiences you have with them?
- What are the major challenges children diagnosed to cancer encounter after being start treatment with their family?
- What are the roles of family during treatment of children diagnosed to childhood cancer?

3. What are the main challenge during treatment of children diagnosed to childhood cancer which affect treatment adherence?
4. What are the socio-economic challenges hamper treatment process of children with childhood cancer at the family level and societal level?

- How do you observe situations and the number of children exposed to childhood cancer? Is increasing or not in your local area? If it is increasing, what do you think? What are the main challenges to children diagnosed to cancer?
- How do you describe children who are diagnosed to childhood cancer such as, their life, character, your image and the magnitude of the problem?
- Where, how and with whom children diagnosed to childhood their time? What do they do together with their friends? What kind of relationship and interactions have among themselves?

5. What are the possible ways of addressing the socioeconomic challenges that hamper treatment adherence of children with childhood cancer in the study area?

- What could be done to reduce challenges during treatment of children with cancer in the study area?
- What are the available opportunities in the treatment of children with this life treating problems with in hospital, community and their families in the study area?
- How many workers (total) does the pediatric oncology have? _____
- How many health professionals are working in this unit? _____
- Would you tell me the most common patients in the unit according to age and sex?

  Age _____ Sex _____
- How many patients a doctor is expected to diagnose per a day? _____
- Is this number proportional to the minimum standard set by experts?
  If no, what impacts did this case is posing to the health service provision and treatment adherence?

  _____

6. Do you think that the physical infrastructure (bed rooms, treatment rooms, materials, pharmacy and others) of the hospital is good enough in all aspects in order to provide a good service?

If no, what impacts did this case is posing to the treatment service provision and treatment adherence.

_____

7. What are the most repeatedly challenge cases in the unit?

   _____

   What the reason for this?

_____

8. What do say about the perception of the society toward the role of modern medicine?

   _____

9. What do you think could be done to improve the pediatric oncology treatment adherence?

_____

Appendix 4: Key observation guide line (pediatric oncology unit)

Jimma University College of Social Sciences School of Social Work

Title: The Socio-Economic Determinants of Children's Cancer Treatment Adherence; The Case of Jimma Medical Center.

My name is Abdulmalik Zakiyu , a student at Jmma University School of Social Work , attending my education in Masters of Social Work. I am conducting a research on the title **"An** assessment of the socio economic factors contributing to children cancer treatment adherence. The Jimma Medical Center, Oromia region state Ethiopia. The objective of this study to assess the socio economic factors contributing to children cancer treatment adherence. Dear interviewee you are selected to provide information that will help achieve the above mentioned objective of the study. I do not need to know your name. With your permission; I wish to ask you the following questions. Please respond as frankly and honestly as possible. Thank you in advance for your time and cooperation.

Observation guide line

Date of Observation …….

Duration of Observation……

Name of the study area…….

- Location of the area/ description of the children diagnosed to childhood cancer
- Check magnitude of the problem and challenges that children exposed to childhood faced during treatment and their family in the study area
- Kinds of coping mechanism used by the children exposed to childhood cancer while treatment with their family in the study area
- Observing behaviors and the day-to-day activities of children diagnosed to childhood cancer in the study area during treatment and after treatment.
- The way in which children with cancer interact with each other and with the other family members in the study area

- The relationship and interaction among children diagnosed to childhood cancer and with family in the study area.
- The physical infrastructure/physical environment which includes as treatment room, registration/card room, toilet, bedrooms, laboratory and pharmacy.
- Observing the treatment process.

Appendix 5: Focus Group Discussion Guide Line

Jimma University College of Social Sciences School of Social Work

Title: The Socio-Economic Determinants of Children's Cancer Treatment Adherence; The Case of Jimma University Medical Center.

My name is Abdulmalik Zakiyu , a student at Jmma University School of Social Work , attending my education in Masters of Social Work. I am conducting a research on the title **"An** assessment of the socio-economic factors contributing to children cancer treatment adherence. The Jimma Medical Center, Oromia region state Ethiopia. The objective of this study to assess the socio-economic factors contributing to children cancer treatment adherence. Dear interviewee you are selected to provide information that will help achieve the above-mentioned objective of the study. I do not need to know your name. With your permission; I wish to ask you the following questions. Please respond as frankly and honestly as possible. Thank you in advance for your time and cooperation.

Focus Group Discussion (FGD) Guide Line

Date of discussion _____ place _____ duration_____

Number of participants _____

- Discussing on the service delivery in the medical center in general and particularly in the pediatric oncology unit.
- Discussion on the understanding about children's cancer, it's impact on their children , on rest family
- Discussion on the impact of pediatric cancer treatment on their socioeconomic.
- Discussion on the reason of treatment non- adherence
- Major challenge they faced before coming to hospital during the coming the medical center after you come medical center in medical center etc.
- Social attitude towards their children and themselves due to the problems.
- Discussion on the role of family size on children treatment adherence
- Discussion on way forward to the problems