Addis Ababa University

College of Education and Behavioral Studies

Department of Special Needs Education

Lived Experiences of Children with Physical and Health Impairments at Jewi Refugee Camp; Gambella Region

By

Belay Tadesse

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This thesis is submitted to the department of Special needs Education in partial fulfillment of the requirement for MA Degree in Special Needs Education

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DECLARATION

I the undersigned, declare that this Thesis is my original work and has not been produced and presented in any other academic institutions. All sources of materials used for the study have been duly acknowledged.

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List of acronyms

ARRA:	Administration for Refugee-Returnee Affairs
DFID:	Department for International Development
E.C.:	Ethiopian Calendar
RADO:	Rehabilitation and Development Association
UNHCR:	United nation Higher Commission for Refugee

Abstract

The main aim of this study was to describe the lived experiences of refugee children with disabilities from their own perspective. Descriptive phenomenological research design was used. Five children with disabilities in which the four have different types of physical disability and one child was living with epilepsy, who were drawn using purposive sampling, were participated in the study. Data were collected using unstructured face to face interview and observations field notes. The interviews were made in ARRA field office of the refugee camp. In order to analyze the data coding, categorizing and organization of major and sub themes were done. After repeated reviews and coding of the data, four major themes were identified. These are 1. Refugee camps as a survival for life, 2. Views of children with disability towards the nature of their disability; 3. Challenges and obstacles within refugee camp, and 4. Outcomes of refugee members' observation and feelings on the life of children with disabilities. The findings revealed that children with disabilities consider the refugee camp as a better place for their life to survive. They also have different understandings on the nature of their disability and their views lied on more of the traditional model of disabilities. The finding also showed that children with disabilities face several challenges as a result of being a child with disability, and these challenges and obstacle lead them to develop several problems because of the prejudice and discriminations. Consequently based on the findings of the study recommendation were forwarded.

CHAPTER ONE

INTRODUCTION

1.1. Background of the Study

Refugees with disabilities are not only affected by the traumatic displacement they experience, but also by the fact that the camp conditions predisposes them to additional challenges of obtaining optimal treatment and adhering to treatment regimens. As a result, their life is synergistically reduced due to both chronic disease and the camp conditions (Preedy & Watson, 2010).

People living with disabilities may be left behind during flight, or may not survive the journey; they are often not identified or counted in registration or data collection exercises; they are excluded from or unable to access mainstream assistance programs and forgotten when specialized services are set up. They are often the most exposed to protection risks, including physical and sexual violence, exploitation, harassment and discrimination. The loss of family members or caregivers during displacement can leave persons with disabilities more isolated and vulnerable than they were in their home communities. And their potential to contribute and participate is seldom recognized. Refugees and displaced persons living with disabilities are amongst the most hidden, excluded and neglected of all displaced persons (Marion & Maurice, 2010, Women's Refugee Commission, 2014).

The United Nations Children's Fund (UNICEF, May 2013), and Women's Refugee Commission (2014) also reported that Persons with disabilities remain one of the most vulnerable and socially excluded groups in any displaced communities and refugees. They may

be hidden in shelters, missed in assessments and not consulted in the design of programs or activities. Persons with disabilities have difficulty accessing humanitarian assistance due to a variety of societal, environmental and communication barriers. This increases their protection risks, including violence, abuse and exploitation. Women and children with disabilities are particularly vulnerable to discrimination, exploitation and violence, and they may have difficulty accessing support and services that could reduce their risk and vulnerability. They are excluded from education and not provided with the support to help them develop to their full capacity.

As reported by The United Nations Children's Fund (UNICEF, May 2013), Children with disabilities are one of the most marginalized and excluded groups of children, experiencing widespread violations of their rights. Discrimination arises not as a result of the intrinsic nature of children's disability, but rather, as a consequence of lack of understanding and knowledge of its causes and implications, fear of difference, fear of contagion or contamination, or negative religious or cultural views of disability. It is further compounded by poverty, social isolation, humanitarian emergencies, lack of services and support, and a hostile and inaccessible environment. Too often, children with disabilities are defined and judged by what they lack rather than what they have. As a result, these children with disability go through miserable life experiences.

The obvious implication is that most disabilities start during childhood and the cause become severe in areas of refugee where active and timely support is less. Children with disabilities often do not get the support and services they need physical rehabilitation, specialized education and social integration are sometimes neglected. Sometimes families, health workers and teachers have not understood the importance of including children with disabilities in normal

patterns of activity. In some refugee situations, rehabilitation services are not provided because nationals do not have access to such services. (UNHCR, 1994).

All these situations lead children with disability to pass challenged life experience within the camps they live in, they pass through different situations as a result of the disability they had which is not experienced by other members of refugees (Women's Refugee Commission, 2014). Thus, this research also aimed to describe the lived experiences of children with disabilities in Jewi refugee camp, which is found in Gambella region.

1.2. Statement of the Problem

According to Light for the world (May 2014) report, persons with disabilities are often missed out in the distribution of aid and services in camps and settlements. They receive less food and non-food items; and health, education and sanitary facilities are often inaccessible. People who become permanently disabled because of conflict or disaster might receive immediate medical treatment but are most often left alone to coping with their impairments afterwards.

Children with disability are often excluded from activities directed at children such as play-groups, pre-school activities and cultural activities (ACPF, 2011; Hurst, 1995). Some people think that children with disability do not understand or are not able to enjoy leisure activities. Therefore, traditional music, dance, arts work, etc. are not made accessible in refugees for children with disability. Consequently, it seems that girls and boys with disability are not included in the participatory work (ACPF, 2011; Ahlen, 1997). In this case, these people fail to understand the needs and feelings of children with disabilities. They, instead of looking life from

the perspectives of children with disability, such peoples focus on the specific impairment and label children with disabilities as not interested and unable to participate in such activities.

Because of such tremendous conditions, refugee children with disabilities suffer a lot to access several social, economic, and legal services. Within this population, there are a number of children with disabilities who experience different life obstacles as they are child in the refugee, on the other hand, they live with additional burden which is social, psychological and many other challenges because of their disability. Children with disabilities are often the first to be abandoned by families and usually the last to receive emergency relief and educational support (UNICEF 2007). In their global report on disability, the World Health organization (2011) also proposed a number of key recommendations for further dismantling barriers that impede persons with disabilities and one of these recommendation stated the importance of conducting research on the lives of persons with disabilities and the barriers that these individuals face (World Health Organization and The World Bank, 2011).

Even though several researches are conducted on the area of disability, little is known about children with disabilities' experience living in refugee camp. Ahlen (1997) also said there is very little knowledge about their situation and life experiences. Moreover, there seems to be a lack of awareness about these children.

Therefore, this study would help increase what is known about living in refugee camp as a child with disability and build new knowledge related to the experience of refugee children with disabilities. Eliciting the voices and hearing the stories of these children can increase our understanding of their everyday lived experiences from their own perspectives. So this research is conducted at Jewi refugee camp which is found in Gambella peoples' regional state. After identifying the camp and fulfilled all the necessary criteria to inter the camp and research on it, I

selected five children with disabilities and made interviews on their lived experiences and observations were done in their current life activities in the camp. My research guide was based on a central research question which is written below:

1.2.1. Overarching Research question:

What is the lived experience of children with disability who are living in Jewi refugee camp?

1.2.1.1. Sub Questions:

- How do they describe life as a child in refugee camp?
- What are their experience being a child with disability and living in refugee camp?

1.3. Purpose of the Study

The purpose of this phenomenological study was to gain an in-depth understanding of the lived experiences of refugee children with disability from their own perspectives.

1.4. Significance of the study

Although there are a number of children with disabilities within refugees in Ethiopia, Little is known about their lived experiences, what life is meant in general from their perspectives and contexts. Eliciting the voices and hearing the stories of these children can increase our understanding of the meaning of the everyday lived experiences from the children's perspectives. With an in-depth understanding of the unique circumstances faced by these children, refugee personnel such as counselors, social workers, teacher and any other organizations working on disabilities can work collaboratively to mitigate some of the challenges and to improve the life and participation of refugee children with disabilities. It is anticipated that the results of this study will help illuminate the lived experiences of refugee children with

disabilities including the supports necessary to care them. The findings may be useful in informing resource allocation and educational inclusion policy within the refugee.

1.5. Scope of the Study

In order to cover all aspects of the lived experience that incorporate all categories of disabilities may require the researchers' skill and may need the collaboration of several stakeholders who have well developed knowledge on the area. So this research focused only on the lived experiences of children with different physical disabilities and epilepsy who are displaced and living in refugee camp. Geographically, the study site was Jewi refugee camp which is found in Gambella region. It is almost 750 kilometer from Addis Ababa and it is located before reaching Gambella town and it is almost 28 kilometer from Jewi to Gambella. The camp is divided in to four zones from A-D with a distance four to five kilometer from each zone such as from zone A to zone B, from B to C… etc; and participants were from Zone A, B, and C, children are not included from zone D because of the distance and lack of transport to reach.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

2.1.Conceptualizing Disability

The definition of disability is highly contentious for several reasons. First, it is only in the past century that the term "disability" has been used to refer to a distinct class of people. Historically, "disability" has been used either as a synonym for "inability" or as a reference to legally imposed limitations on rights and powers. Many different characteristics are considered disabilities. Paraplegia, deafness, blindness, diabetes, autism, epilepsy, depression, and HIV have all been classified as "disabilities."

The term covers such diverse conditions as the congenital absence or adventitious loss of a limb or a sensory function; progressive neurological conditions like multiple sclerosis; chronic diseases like arteriosclerosis; the inability or limited ability to perform such cognitive functions as remembering faces or calculating sums; and psychiatric disorders like schizophrenia and bipolar disorder (Abera, 2013).

There seems to be little about the functional or experiential states of people with these various conditions to justify a common concept; indeed, there is at least as much variation among "disabled" people with respect to their experiences and bodily states as there is among people who lack disabilities. Indeed, some have questioned, in part because of this variation, whether the concept of disability can do much philosophical work (Beaudry, 2016).

Disability can be constructed and defined in different ways, and different aspects of people's lives are amassed under the term *disability* (pathological conditions and illnesses, age-related deterioration, injuries and adjustment problems, social differences, and deviant behavior).

Those experiencing a reduction in their adeptness can feel discriminated against. Such discrimination can involve situations that subject the individual to a greater risk of vulnerability, insult, or attack, but also those that restrict access to situations of wellness, a sense of self or collective identity, or a focus on one's individuality or personal needs. In other words, a complex reality is encompassed with the term *disability,* and this complexity is far from easy to administer categorically in the policy arena. No single theory or perspective can capture disability in a satisfactory way. Analyses of this phenomenon require a broader theoretical framework and approach (Phillips, 2009; Marianne, 2009).

Defining disability is complex and controversial. It is a universally used, yet ambiguous term. Categorizing the level of functional limitation, impairment or disability is confounded by the availability of assistive devices, personal help, cultural expectations and environmental modifications and adaptations. Though arising from physical or intellectual impairment, disability has social implications as well as health ones. A full understanding of disability recognizes that it has a powerful human rights dimension and is often associated with social exclusion, and increased exposure and vulnerability to poverty. Disability is the outcome of complex interactions between the functional limitations arising from a person's physical, intellectual, or mental condition and the social and physical environment. It has multiple dimensions and is far more than an individual health or medical problem. On this basis, disability is 'long-term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community' (DFID, 2010; Rockhold, 2010**)**.

The United Nations Convention on the Rights of Persons with disabilities defines "Persons with disabilities as follows: include those who have long-term physical, mental,

intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". It further stated that persons with disabilities do not constitute a homogenous group. They come from all ages, ethnicities, gender, religious and economic classes. Impairments may be congenital or result from birth, accidents, physical or psychological traumas, violence and abuse, disease, psychiatric disorders, poor access to health care, bad nutrition. Resulting disabilities can be transitory or permanent, but they tend to be magnified in situations of emergence and movements of populations (UNHCR, 2009).

According to the International Classification for Functioning Disability and Health (ICF), individual's functionality, disability and health are assessed and classified at three levels: impairment of the body function and structures: example, missing a leg; activity limitations and participation restriction: example, unable to dress oneself or difficulties with interpersonal relations, and the environmental factors: example, attitudes or systems and policies (Rockhold, 2010).

2.2.Causes of Disability

Poor nutrition, dangerous working and living conditions, limited access to vaccination programs, and to health and maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, war and conflict, and natural disasters all cause disability. Many of these causes are preventable (Tamashiro, 2010; Coleridge 1999). According to estimates by the World Health Organization (WHO), as many as 20 million women a year suffer disability and long-term complications as a result of pregnancy and childbirth. The most common causes of motor disability are injuries from accidents on the road, at home, or the

workplace; war and violence, including landmines; birth trauma; and infectious diseases such as polio and leprosy. Children are often disabled as a result of malnutrition (DFID, 2010).

2.3.The Different Understandings of Disability

Definitions of disability vary according to the conceptual framework or understanding is being applied. It can be constructed in relation to several basic interpretations or understandings of the phenomenon. Instruments and methods of assisting a person with disability are likely to be based on different underlying interpretations of what constitutes the "problem" of a disability. Each interpretive model or understanding approaches disability from a unique *viewpoint.* From this viewpoint, different limitations and facts are regarded as appropriate when defining disability. Different models assume different ideological principles for how welfare for persons with disabilities can be achieved (Beaudry, 2016).

2.3.1. Models of Disability

Models of Disability are tools for defining impairment and, ultimately, for providing a basis upon which government and society can devise strategies for meeting the needs of people with disability. They are often treated with skepticism as it is thought they do not reflect a real world, are often incomplete and encourage narrow thinking, and seldom offer detailed guidance for action. However, they are a useful framework in which to gain an understanding of disability issues, and also of the perspective held by those creating and applying the models (Beaudry, 2016; Marianne, 2009).

Models of Disability are essentially devised by people about other people. They provide an insight into the attitudes, conceptions and prejudices of the former and how they impact on the latter. From this, Models reveal the ways in which our society provides or limits access to work, goods, services, economic influence and political power for people with disabilities.

The Traditional model/Pre-Modern Models

Traditionally, in many cultures around the world, people with physical, sensory or mental impairments were thought of as under the spell of witchcraft, possessed by demons, or as penitent sinners, being punished by God for wrong-doing by themselves or their parents (Marianne, 2009). In many societies early understandings of disability were based on religious fear. People with disability represented the punishment of an angry God. Parents had transgressed or sinned and their disabled child was their "cross to bear". Accordingly, people with disabilities were feared and loathed and were subject to cruel treatment. Often families concealed a disabled child so as to avoid retribution or ridicule from their neighbors. Children with disabilities were killed or abandoned (Slee, 2016; Tirusew, 2005).

The Tragedy/Charity Model

According to Slee (2016) and Beaudry (2016), the Tragedy/Charity Model depicts people with disability as victims of circumstance, deserving of pity. This and Medical Model are probably the ones most used by non-disabled people to define and explain disability. Traditionally used by charities in the competitive business of fund-raising, children in need appeals in which disabled children are depicted alongside young "victims" of famine, poverty, child abuse and other circumstances. Whilst such appeals raise considerable funds for services and equipment which are not provided by the state, many people with disability find the negative victim-image thoroughly offensive. In fact Children in Need have been described as "televisual garbage …" oppressive to people with disability. Some go as far as interpreting the tragic portrayal as a means of maintaining a flow of donations and keeping able-bodied people in work.

The Tragedy/Charity Model is condemned by its critics as dis-enabling, and the cause of much discrimination. Because people with disability are seen as tragic victims, it follows that they need care, are not capable of looking after themselves or managing their own affairs, and need charity in order to survive (Slee, 2016).

From tragedy and pity stems a culture "care". Although highly praiseworthy in many respects, it carries certain dangers. Numerous charities exist to support and care for people with a particular type of disability, thereby medically classifying, segregating and often as with the Medical Model institutionalizing many people with disability (Eva,1997).

The idea of if being recipients of charity lower the self-esteem of people with disabilities. In the eyes of "pitying" donors, charitable giving carries with it an expectation of gratitude and a set of terms imposed upon the beneficiary. The first is patronizing; the second limiting upon the choices opens to people with disability. Also, employers will view people with disability as charitable cases. Rather than address the real issues of creating a workplace conducive to the employment of people with disabilities, employers may conclude that making charitable donations meets social and economic obligations (Slee, 2016; The African Child Policy Forum, 2011).

This is not to advocate dismantling charities and outlaw caring, charitable acts, which enrich our society and bring badly needed funds. But we do need to educate charity managers and professionals to review the way they operate and ensure that funds are channeled to promote the empowerment of people with disability and their full integration into our society as equal citizens requiring our respect and not our pity (Marianne, 2009).

The Medical Model

With the Age of Enlightenment in the 18th century, came a more scientific understanding of the causes of impairment and, with it, a sense of confidence in medical science's ability to cure, or at least rehabilitate, people with disabilities. People with disabilities (often for social or political reasons) were deemed incurable and placed in long-stay institutions and special schools (or, today, in day-care centers). A notion of 'normality' was invested with great pseudo-scientific significance. It was based on assessments of impairments from a deficit point of view against normality: what one cannot do, instead of what one can do. This has been called 'medical model' (or 'individual model') This is not to deny the very necessary role of medical science in keeping many people with disabilities alive, and reducing their pain and discomfort, but it is to argue that disabled people should not be reduced to just their impairments (Slee, 2016).

The 'medical model' sees people with disabilities as the problem. They need to be adapted to fit into the world as it is. If this isn't possible, then they should be shut away in a specialized institution or isolated at home, where only their most basic needs are met. The emphasis is on dependence, backed up by the stereotypes of disability that bring out pity, fear and patronizing attitudes. Usually, the impairment is focused on, rather than the needs of the person. The power to change people with disabilities seems to lie with the medical and associated professions, with their talk of cures, normalization and science. Often, people with disabilities' lives are handed over to these professionals. Their decisions affect where people with disabilities go to school; what support they get; where they live; what benefits they are entitled to; whether they can work; and even, at times, whether they are born at all, or allowed to have children themselves (Slee, 2016; Marianne, 2009).

The medical model views disability as an individual problem. The person with a disability has to be "changed" to "fit" in the society. She or he is often seen as sick, needing medical care and curative treatment. However, when people with disability are seen as sick and "abnormal" this further isolates them and attitudes in society will not change (Eva, 1997; Slee, 2016).

The Social Model

In recent years, the disability movement has advocated a different way of looking at disability, which they call the 'social model'. This starts from the standpoint of all adult with disabilities' and children's right to belong to and be valued in their local community. Using this model, you start by looking at the strengths of the person with the impairment and at the physical and social barriers that obstruct them, whether at school, college, home or work. The 'social model' defines 'impairment' and 'disability' as very different things.

Impairment is the loss or limitation of physical, mental or sensory function on a long-term or permanent basis. Whereas, disablement is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers. (Slee, 2016; Marianne, 2009).

Impairment and chronic illness exist and sometimes pose real difficulties. Supporters of the disability movement believe that the discrimination against people with disabilities is socially created and has little to do with their impairments, and that, regardless of the type or severity of their impairments; people with disabilities are subjected to a common oppression by the non-disabled world (Marianne, 2009). People with disabilities are often made to feel it's their own fault that they are different. If some part, or parts, of your body or mind are limited in their functioning, this is simply impairment. It doesn't make you any less human. But most people

have not been brought up to accept all people as they are; in other words, to value difference. Through fear, ignorance and prejudice, barriers and discrimination develop which disable some people. These are often reinforced by images in the media. Understanding this process allows people with disabilities to feel good about themselves and empowers them to fight for their human rights (Marianne, 2009; Mirza, 2011).

2.4.Efforts to Prevent and Intervene disability

A large amount of disability is preventable, often through relatively simple, low cost interventions. The general improvement of living conditions and standards will itself reduce the incidence of disability. General improvements to health services will also bring major benefits, both in reducing the risks of disability and mitigating its effects when it occurs. Programs specifically aimed at reducing or eliminating specific diseases and conditions can also have a massive impact (DFID, 2010).

Children placed away from home need increased care and protection, and institutional cultures, regimes and structures that exacerbate the risk of violence and abuse should be addressed as a matter of urgency. Whether they live in institutions or with their families or other caregivers, all children with disabilities should be viewed as a high risk group in which it is critical to identify violence. They may benefit from interventions such as home visiting and parenting programs, which have been demonstrated to be effective for preventing violence and mitigating its consequences in children without disabilities. The effectiveness of such interventions for children with disabilities should be evaluated as a matter of priority (Lisa, et al., 2013).

2.5.Experience of children with Cultural and Environmental Deprivations

Cultural deprivation is a term referring to the absence of certain expected and acceptable cultural phenomena in the environment which results in the failure of the individual to communicate and respond in the most appropriate manner within the context of society. Deprivation has a negative impact on educational attainment and other developmental aspects of a child, leaving young people with fewer qualifications and skills which in turn affect future employment.

Environmental and cultural deprivation is commonly associated with a range of other factors which can influence children's outcomes. These include: ill health; family stress; low levels of parental education and parental involvement in their children's education and development; low levels of cultural and social capital; and low aspirations. Children from deprived families and environments are at greater risk of low birth-weight, which influences their cognitive and physical development, and are more likely to suffer from ill health (Deprivation and Education, 2009).

Ridge (2009) presented that the experience of poverty in childhood can be highly damaging and the effects of poverty are both pervasive and disruptive. Poverty permeates every facet of children's lives from economic and material disadvantages, through social and relational constraints and exclusions, to the personal and more hidden aspects of poverty associated with shame, sadness and the fear of difference and stigma.

The deprivation dimension should be understood as denoting the lack of material conditions and services generally held to be essential to the development of children's well-being. These may include (but are not limited to) the following:

- Food
- Health

- Safe drinking water
- Shelter
- Sanitation facilities
- Education

These are important components to understand deprivation, and are applicable to humans of all ages, cultures and backgrounds. However, its importance with regard to children cannot be underestimated, as they are often far more gravely affected by deprivation in these areas than adults, due to the very nature of child development. Childhood is a once-and-for-all window of opportunity for physical, cognitive, psychological, emotional and social development. Though adults may be able to overcome a period of deprivation, children without adequate food, water or shelter may suffer from stunting and/or illness that can potentially affect their entire life (Daniel, Mark, & Thomas, 2005; Deprivation and Education, 2009).

According to Ridge (2009) on the study of children's and families' experiences of poverty, some forms of deprivations experienced by children are:

- Economic deprivation: children were anxious about the adequacy of income coming in to their households and were afraid there would not be enough money for them and for their family's needs;
- Material deprivation: children lacked important childhood possessions, like toys, bicycles and games, and they also expressed concerns about being short of essentials and everyday items, like food, towels, bedding and clothing;
- Social deprivation: poverty restricted children's chances to make and sustain friendships, and reduced their opportunities for shared social activities due to the costs of

attending social events, inadequate and expensive transport provision and the expense of hosting social occasions within their own homes;

- School deprivation: children experienced restricted opportunities at school, largely through an inability to pay for resources such as study guides and exam materials, and restricted social opportunities through an inability to pay for school trips and other social activities. Inability to pay for compulsory items, such as uniforms, could also lead to conflict with teachers and disciplinary action;
- Tensions with parents: conflicts sometimes arose with parents who were under severe financial pressure, or who sometimes had to work long hours or rely on childcare that children did not enjoy;
- Additional responsibilities: children in low-income working families were often taking on additional responsibilities in the home, including housework and caring responsibilities, or engaged in paid work themselves to ease financial pressures at home and to gain access to their own money;
- Poor quality housing: this affected children's health and wellbeing, and meant that children had difficulties in sleeping, studying or playing at home;
- Homelessness: children experienced considerable anxiety about the quality of their temporary accommodation including a lack of privacy and no space for play. This affected their health, their school lives and their social participation;
- Poor neighborhoods: deprived neighborhoods created particular problems for children who described then as insecure and sometimes dangerous. They experienced a lack of safe space for play and a dearth of local and low-cost leisure facilities;

- Living in rural areas meant that disadvantaged children lacked social opportunities for shared play, were reliant on inadequate and costly public transport, and were unable to meet the high costs of participation. This meant that children often felt confined within their local environments.

2.6.Refugee Camps as a Survival for Life

The history of migration has its roots in population movements as one of the fundamental factors in human survival and this is conceptualized as the history of peoples struggle to survive and to prosper, to escape insecurity and poverty, and to move in response to opportunity (Juss, 2006 cited in Mulegna, 2010; HNHCR, 2009)

Children and youth are particularly vulnerable during periods of war and social conflict. Learners from refugee or war-affected backgrounds have often lived through some terrible experiences. In the last decades, millions of children have witnessed and felt the terrible effects of war.

The recent developments in warfare have made it much more dangerous for children. Millions of children have been killed, disabled, left homeless, or separated from their parents, and many millions have been psychologically traumatized. Children experience many different types of trauma during war and conflict (Manitoba Education, 2012; Tamashiro, 2010).

Armed conflict is not only responsible for directly killing and injuring civilians through infliction from weapons, but it also has widespread indirect varied effects. Indirect deaths and injury are usually caused by the degeneration of social, economic, and health conditions in conflict affected areas (Geneva Declaration 2008). Conflict creates increased vulnerability to infectious diseases and malnutrition because of diminished access to clean water, inadequate food and shelter, and a lack of access to basic and obstetric health care.

Conflict and heightened insecurity in resource strained areas adds pressure to already fragile health systems. Violent attacks on medical and other social facilities severely limit civilian access to health services (UNICEF, April 2009). Elevated mortality rates persist even after the conflicts end, and recovery is especially protracted in places with inadequate health infrastructure. Indeed, illness, injury, and death often occur in the months and years after the conflict ceases. Over time, victims of armed conflict can experience detrimental long term physical and mental disabilities.

In serving refugees and displaced population worldwide, the UN gave full responsibilities to the United Nations High Commission for Refugees (UNHCR) created in 1950, is the world's largest organization with the sole responsibility of protecting and assisting refugees. In this regard, The UNHCR had well defined articles to manage and handle cases. According, to article 1of the Statute of the Office, the main task of the High Commissioner is to provide international protection to refugees and to seek durable solutions for refugees by assisting governments to facilitate the voluntary repatriation of refugees, or their integration within new national communities. The High Commissioner's function is qualified as "entirely non-political" and "humanitarian and social." In fulfilling its protection function, the tasks of the High Commissioner as set out in the Statute, include:

- ✓ Promoting the conclusion and ratification of international conventions for the protection of refugees, supervising their application and proposing amendments;
- ✓ Promoting measures to improve the situation of refugees and to reduce the number requiring protection;
- ✓ Assisting efforts to promote voluntary repatriation or assimilation within new national communities;

- ✓ Promoting the admission of refugees to the territories of States;
- ✓ Facilitating the transfer of the assets of refugees; obtaining from Governments information concerning the number and conditions of refugees in their territories, and the relevant laws and regulations;
- ✓ Keeping in close touch with Governments and intergovernmental organizations;
- ✓ Establishing contact with private organizations dealing with refugee questions;
- ✓ Facilitating the coordination of private efforts.

Protection tasks have diversified even further over the years since the drafting of the Statute (UNHCR, 2005).

The increasing number of social and environmental disasters outflow peoples from their environments and now days, number of refugees are extremely high. In this case there are numerous organizations who are working collaboratively with UNHCR for the protection and support of refugees and displaced populations. The international community responds to natural and manmade disasters with financial, material and technical assistance. This is intended not only to save lives during emergencies, but also to help build capacity to prevent and avoid future disasters (DFID, 2010; Mulugeta, 2011).

Providing services and cares to refugees is a complex task that involves many stakeholders, including international institutions, national governments, and NGOs. However, lack of coordination makes delivery of high-quality care difficult and costly. Communication lapses result in deletions or duplications of services. While the organization that leads coordinating efforts may vary depending on the context, the one providing the largest funds and resources will generally be in the best position to assume this role. The lead agency should also have mechanisms for delegating responsibilities to cover and monitor services and programs

(Aisha, 2016). To better care the lives of refugees, and displaced population, National Intelligence and Security Service Administration for Refugee-Returnee Affairs (ARRA), Rehabilitation and Development Organization (RADO), and the International Rescue Committee (IRC) and other are involved in health care, reproductive health services, rehabilitation and HIV/AIDS prevention and response (Mulugeta, 2011).

Unless these organizations move to exercise in collaboration, it will be very difficult to reach for more than 24 million people who are refugees or displaced persons fleeing war, conflict and discrimination. Around one third of these are children and adolescents. Infants and children are amongst the most vulnerable in situations of war and conflict. Children are both direct and indirect victims of war and conflict and are particularly vulnerable to exploitation and abuse. It is clear that these vulnerable children especially children with disability should get access to care and protection. In order to reduce the effects of trauma and insecurity, refugee camps are a place for such children and must have coordinated responses and jointed support (Trauma and Grief Network, n.d.).

2.6.1. Accessibility and support for children with disabilities within refugee camp

The world's refugee populations are currently increasing in a alarming rate, the large majority of whom reside in developing countries. The quality and availability of services for refugee populations varies according to the geographic setting, availability of adequate resources, and proper training of service providers but in most cases, people with disabilities did not get emphasis and are not prioritized during the service delivery (Aisha, 2016).
Refugee camps are artificial environments where everyone is restricted in their freedom of movement. They are overcrowded and epidemics such as measles, dysentery, meningitis and

cholera have been found to be major killers. The bigger the camps, the more pronounced these effects. A major consequence of life in a refugee camp is the almost inevitable exposure to a sub-nutritional diet. Epidemics of nutrition related diseases are common in camps. These include night blindness, beri-beri, pellagra, and scurvy. They are caused by the lack of micro-nutrients - vitamins in the rations supplied by international aid. There is a growing body of evidence that suggests that a child's ability to learn is permanently affected by prolonged state of malnutrition and through time, they develop disability. There is even the suggestion that growing up undernourished may be the reason why so many refugee women from southern Sudan have pelvises too small to deliver babies normally (Barbara, August 2000).

Refugees with disabilities are a particularly vulnerable population with specific rehabilitation and health needs. The journey out of violent and unstable areas can be dangerous and exhausting with deleterious consequences for person with disability during travel through unsafe, unsanitary, and poorly resourced settings. Even after they reach a border, refugees with disability face many challenges integrating into new communities, adapting to altered lifestyles, and dealing with the effects of traumatic experiences. Various international NGOs, governments, and local organizations are working together to provide basic services in order to manage the overload of these refugees amid inadequate resources, as well as to stem the spread of infectious diseases and potential outbreaks. Likewise, interagency coordination and training in cultural competency becomes even more critical (Aisha, 2016).

All children are vulnerable in armed conflict. However, children with disability who are staying in a war zone or are fleeing from one area to the other are particularly at risk. The rights of these children are never a priority. On the contrary, they are often the last to be considered (Eva,1997) The needs of children with disability are basically the same as those of other

children; but in situations of violence and conflict it becomes more difficult to ensure that these needs are met and that adequate protection is provided for more vulnerable children. It would be expected conflicts to increase the number of impaired children, and to make life more difficult for those with existing impairments. Their problems are exacerbated because most conflicts occur in developing countries, where children are already at a higher risk of impairment due to poverty and limited care, and where resources for disability services usually do not have priority (Richman, 1995 cited in Eva, 1997). Even if disabilities are included in refugee profiles, all kinds of disabilities are not covered. For example, the non-visible ones like epilepsy or hearing impairments tend to be neglected (Eva, 1997).

In the Kakuma refugee camp (in Kenya) also there were no services for people with disability. This caused the people with disability start to organize themselves. They identified their needs, primarily literacy training and vocational training, and tried to make use of existing resources within the camp. Literacy training started under some trees in the camp. In 1993 an international organization started supporting the group. Different kinds of activities were carried out, for example literacy training, vocational training, carpentry training and informal counseling and group discussions. In 1994, however, people in the camp realized that the majority of the people with disability living there were not participating in the activities. The women and children with disability were not benefiting from training and other activities. The focus of the activities was on men who had been injured during the war and physically disabled. People with other types of disability were not benefiting either (Women's Refugee Commission, 2014).

Children with disability should be included in the planning, implementation and evaluation of the community based services. Girls and boys with disabilities and their families

should be encouraged to take an active part in order to make sure that their needs and rights are addressed (Juma, 1996). Organization like RADO also provides health care and physical rehabilitation services to refugees with disability inviting specialists for eye, nose and throat patients. RADO sometimes provides treatments for people with disability, particularly those with sights and hearing impairment, inviting specialist to the camp, provides rehabilitation equipments including walking crunches and wheelchairs (Mulugeta, 2011).

In addition to these, Women's Refugee Commission (2014) pointed out that Studies conducted in different countries revealed the problem that the physical layout and infrastructure of camps impeded access for persons with disabilities to facilities and services, including schools, health clinics, latrines, water points, bathing facilities and food distribution points. Difficulties with physical access and the poor design of camp buildings, including shelters, affected all aspects of daily life and increased the isolation of persons with disabilities. This was particularly the case in refugees of many urban and rural areas. On the other hand Researchers did find some positive examples of adaptations to improve physical access; in Dadaab refugee camp (Kenya), for example, wheelchairs were designed with special wheels for use on the sandy terrain.

Within several refugee camps mainstream services were either inappropriate or did not cater for the specific needs of persons with disabilities. Food distribution systems were inaccessible for persons with disabilities in several countries, and there were no additional or special food rations. Mothers in Nepal and Yemen, for example, said that they could not get specially formulated food for children with cerebral palsy and cleft palates. Refugees in Yemen said that people with visual impairments were cheated during food distributions, or had their rations stolen. In Dadaab, on the other hand, the World Food Program gave refugees with

disabilities priority during food distributions so they did not have to wait in long queues, and members of the community were mobilized to help collect food rations for persons with disabilities.

In addition, educating children with disabilities in refugee setting there was a lack of special needs support staff or training for mainstream teachers and a lack of appropriate teaching aids, flexible curricula and assistive learning devices and school buildings were physically inaccessible. In Yemen, for example, children with visual and hearing impairments did not have spectacles or hearing aids which made it very difficult for them to continue at school. In some countries school attendance rates for children with special learning needs were high. In refugee camps in Nepal and Thailand there were successful early childhood intervention programs to identify children with disabilities and help them integrate into mainstream schools. Through early childhood intervention programs, refugee children with disabilities could be referred to appropriate health services, and parent support groups were a positive starting point to provide psychosocial support to parents of children with disabilities. (Women's Refugee Commission, 2014; Rachel, 2005).

2.7.Challenges and Obstacles of Children with Disability Living in Refugee Camp

Understanding the extent of violence and disability related challenges against children with disabilities is an essential first step in developing effective programs to prevent them from becoming victims of violence and to improve their health and the quality of their lives (Women's Refugee Commission, 2014; Mulegna, 2010).

Many refugee children have watched family members being raped, tortured or murdered, or indeed have been severely abused themselves. Many have experienced the disappearance or imprisonment of family members. Most young refugees with disabilities have experienced high

levels of anxiety, had to flee from their homes, often on their own, and will have travelled through a number of countries due to living in situations of serious poverty and deprivation (Rachel, 2005).

People with disabilities have been historically neglected within humanitarian programs targeted at displaced populations, resulting in serious unmet needs and diminished opportunities for participation in various life domains (Kett & van Ommeren, 2009 cited in Mirza, 2011). Refugees with disabilities are not only affected by this traumatic displacement they experience, but also by the fact that the camp conditions predisposes them to additional challenges of obtaining optimal treatment and adhering to treatment regimens. As a result, their health condition is also synergistically reduced due to both chronic disease and the camp situations (Preedy & Watson, 2010). In addition to these, people with disabilities who are denied educations are then unable to find employment, driving them more deeply into poverty. Breaking out of the vicious cycle of poverty and disability becomes more and more difficult (DFID, 2010).

2.7.1. Challenges and obstacles related with social and physical environment of the refugee camp

Many refugee children spend their entire childhood in displacement, uncertain about their future. Children whether refugees, internally displaced or stateless are at greater risk than adults of abuse, neglect, violence, exploitation, trafficking or forced recruitment into armed groups. They may experience and witness disturbing events or be separated from their family. At the same time, family and other social support networks may be weakened and education may be disrupted. These experiences can have a profound effect on children (Preedy & Watson, 2010). Gender is also a crucial factor: Girls are less likely than boys to receive care and food and are more likely to be left out of family interactions and activities. Girls and young women with

disabilities are ‘doubly disabled’. They confront not only the prejudice and inequities encountered by many persons with disabilities, but are also constrained by traditional gender roles and barriers. Girls with disabilities are also less likely to get an education, receive vocational training or find employment than are boys with disabilities or girls without disabilities. Girls with disability living in refugee settings are particularly exposed to sexual violence because of their inability to protect themselves. The abuse is also less often detected. For example; girls with speech impairments may not be able to tell anyone about the abuse; girls with visual impairments may not be able to identify the abuser; and girls with learning difficulties may not understand their rights (Eva, 1997). Refugee and displaced children and adolescents with disabilities may be at increased risk of abuse and exploitation for a variety of reasons; these may include separation from their families, lack of access to education, and the need to take on adult responsibilities such as caring for siblings (Action for the Rights of Children, n.d.; Eva, 1997; Beaudry, 2016).

Children with disabilities encounter different forms of exclusion and are affected by them to varying degrees, depending on factors such as the type of disability they have, where they live and the culture or class to which they belong. (The State of the World’s Children, 2013). According to Lisa, et al. (2013), Children with disabilities are three to four times more likely to be victims of violence. Children and adults with disabilities often face a wide range of physical, social and environmental barriers to full participation in society, including reduced access to health care, education and other support services. They are also thought to be at significantly greater risk of violence than their peers without disabilities.

2.7.2. Facing Parent related challenges in Refugee camp

According to Barbara (August 2000), within the community of refugee camp many families are broken, children being cared for by only one parent, or without either parent. Sometimes a child has to act as head of family, trying to care for its younger siblings. In camp situations, children also lose role models to guide their development. Even where both parents are present, these children grow up under abnormal conditions. To feed their children, parents are dependent on hand-outs from strangers. Parents are deprived of their authority; their roles as carers and breadwinners are undermined by their dependence on a system over which they have no control. Parents become degraded in the eyes of their children. Parents suffer the further humiliation of standing in queues to get food, being forced to manipulate the system to get extra ration cards in order to have enough food. They may also suffer from enforced idleness which contributes to the loss of self-esteem, particularly that of men.

2.7.3. Experience of prejudice and discrimination towards children with disability in refugee camp

Children with disability are often excluded from activities directed at children such as play-groups, pre-school activities and cultural activities. Some people think that children with disability do not understand or are not able to enjoy leisure activities. Therefore, traditional music, dance, arts work, etc. are not made accessible for children with disability. Although participatory methods are a common working tool and there is some awareness about disability-related issues, it is difficult to reach children with disability. Programs directed at people with disability tend to focus on adults (Eva,1997). Disability limits access to education and employment, and leads to economic and social exclusion as well as people tend to experience negative attitude towards person with disabilities (DFID, 2010).

Mdziniso (2001) points out that throughout Africa people with disabilities are seen as hopeless, helpless and a curse in society, thus the African culture and belief have not made matters any easier for them. The belief of avoiding whatever is associated with evil has from early history affected people's attitude towards people with disabilities, simply because disability is associated with evil. In supporting the foregoing statements concerning the disability, Abosi (2001) states that most of these negative attitudes are more of misconceptions that stem from the lack of proper understanding of disabilities and how they affect the functioning of the affected. As a result, negative attitudes tend to constitute stumbling blocks towards the total acceptance of the disabled. Bender (2008), states that a disability may generally be defined as a condition which may restrict a person's mental, sensory, or mobility functions to undertake or perform a task in the same way as a person who does not have a disability. It does not mean that a person with a disability is unable to perform all the important requirements of a job and exceed the expectations of their employer. Some people have attitude that people with a disability are totally different and therefore to be treated differently. Unfortunately, this kind of stereotyping is in itself a form of discrimination.

Livneh (1982) briefly described that provoking behaviors by person with disability on discriminatory practices towards them that invite prejudice may be categorized into two general classes:

1. Prejudice by invitation: Specific behaviors by individual with disability (being dependent, seeking secondary gains, acting fearful, insecure, or inferior) create and strengthen certain prejudicial beliefs in the observer. These behaviors is traced to person with disabilities' expectations of being treated in depreciating ways, and as a result set themselves up in situations in which they will be devalued.

2. Prejudice by silence: Lack of interest on person with disability's part or lack of effective public relations campaigns or self-help groups representing the interests and concerns of specific disability groups to combat the public's ignorance is a way of fostering stereotypic and negative attitudes on the latter's part.

He continued that several disability-connected issues were reported as affecting attitudes toward person with disability that aggravate prejudices and discrimination. Among the major heightened issues can be found:

1. Functionality vs. organicity of disability: It is found that a dichotomy exists between the public's perceptions regarding certain personality traits attached to functional (alcoholism) or organic (blindness, cancer) disabilities. Those disabilities having the least functional implications were also those reacted to least negatively.

2. Level of severity: Usually the more severe a disability is, the more negatively it is. Severity is, of course, related to level of functional limitation involved.

3. Degree of visibility: Generally, the more visible a disability is, the more negative an attitude it tends to trigger.

4. Degree of cosmetic involvement: Generally, the more the cosmetic implication inherent in the disability, in terms of aesthetic characteristics, the least favorably it is reacted to.

5. Contagiousness vs. non-contagiousness of disability: The more contagious a disability is, the more fear of personal contraction is aroused and the more negative, therefore, is the ensuing reactions that increase the action of discrimination and prejudice.

6. Body part affected.

7. Degree of predictability. On the whole, the more curable and therefore predictable the disability is, the less negatively it is perceived.

Prejudiced attitudes toward people with disability and all minority groups are not innate. They are learned through contact with the prejudice and ignorance of others. Therefore, it is appropriate that the challenge to discrimination against disabled people should begin in schools. The fight for the inclusion of all disabled people, however severe their impairments, in one mainstream social system, will not make sense unless people understand the difference between the social and medical models of disability (Phillips, 2009).

These prolonged and cumulative stressors have a lasting and negative collision on children, young people and families. Research has shown that exposure to severe trauma, such as violence and ongoing fear of safety, have lasting negative impacts on the physical and mental health of children that last into adolescence and adulthood. Research has also shown that there is a cumulative effect in terms of trauma and adversity. That is, the greater number of traumatic or adverse experiences that a child has, the more likely they are to develop a trauma response or develop physical and or mental health difficulties (Barbara, August 2000).

Trauma manifests in many different ways and there are many difficulties that a child may face as a result of trauma, that may be interpreted by others as being a behavioral or emotional problem of the child (Trauma and Grief Network, n.d.).

CHAPTER THREE

METHOD

3.1.Research Design

This study took a qualitative approach in which the data were collected from key participants to describe the lived experiences of children with disabilities in Jewi refugee camp; which is found in Gambella region. In order to better describe the lived experience, descriptive phenomenological research design was a strategy of inquiry for data collection and analysis.

In short, descriptive, phenomenological type of qualitative method was utilized. Descriptive phenomenology, in correspondence to phenomenology, was developed by Husserl (1962). He gave emphasis to describing the human experience. Descriptive phenomenologists are firm on a careful description of ordinary conscious experience of a person's everyday life.

This approach necessitated me to return the research findings to participants to discuss it with them, thus validating the findings (Shosha, 2012). As Crewswell (2007), Marshal and Gretchen (1999), and Gay, Geoffrey, and Peter (2012) stated, phenomenological research describes the meaning of the lived experience from the perspective of the participant and seeks to achieve a deep understanding of the phenomenon by rigorous, systematic examination of it. Thus, such strategy enables me to understand and describe the lived experiences of children with disabilities in Jewi refugee camp.

3.1.1. The Interrelations of Descriptive phenomenology and Lived Experiences

. In a broad sense, the purpose of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience (Speziale & Carpenter, 2007). Lived experiences involve the immediate consciousness of life's events prior to reflection and without

interpretation, and are influenced by those things that are internal or external to them. It is the lived experience that gives meaning to each individual's perception of a particular phenomenon and thus presents to the individual what is true or real in his or her life. A phenomenological analysis does not aim to explain or discover causes. Instead, its goal is to clarify the meanings of phenomena from lived experiences. As such, phenomenology offers an important shift from a positivist cause-effect focus to one of human subjectivity and discovering the meaning of actions. Phenomenology practiced within a human science perspective can thus result in valuable knowledge about individuals' experiences. (Giorgi, 1997)

This study was situated within a phenomenological framework, which assisted in describing the essence of the lived experience of children with disability who are living in Jewi refugee camp. Phenomenology is regarded as both a method and way of thinking and perceiving (Speziale, & Carpenter, 2003). The purpose of phenomenological inquiry in this study was to describe the lived experience of children with physical disability and epilepsy by identifying the essence of the phenomenon through the description of the everyday lived experience (Rose, Beeby, & Parker, 1993). In this regard the descriptive phenomenological method was utilized. I analyzed the descriptions given by participants and divided them into meaning-laden statements, gathering those meanings that are essential to the construct of the phenomenon being studied. Consequently, I was able to bring to written description of the phenomenon.

A descriptive phenomenological approach is used when little is known about an issue and the aim of the study is to make clear and understand the most essential meaning of a phenomenon of interest from the perspective of those directly involved in it (Giorgi, 1997). In view of the aims underlying each of the major phenomenological approaches, the use of a descriptive phenomenological approach is better suited to examining the experiences of South

Sudanese refugee children with different physical disability and epilepsy who are fled to Ethiopia and living in Jewi refugee camp. This approach was especially appropriate considering the paucity of research examined this particular cohort of children with disability and the need for a fundamental understanding of their lived experience. Therefore, a descriptive phenomenological approach integrating with the step by step thematic analysis developed by Braun and Clarke's (2006), accurately served the description of the lived experiences of children with disability who are living in Jewi refugee camp.

3.2.Research Area and Participants

This research was conducted in Jewi refugee camp which is found in Gambella region: Ethiopia. Jewi is almost 750 kilometer from Addis Ababa and it is found before reaching Gambella town. it is around 28kilometer from Gambella. Jewi Refugee Camp was established on 15 March 2015 and hosts refugee relocated from Leitchuor and Nipnip following floods that left refugees in both locations homeless. This led to establishment of the camp which offered home for refugees to settle and live in safety and dignity. The camp population comprises of over 56,000 refugees mainly from South Sudan's Unity, Upper Nile and Jonglei states. The refugees are predominantly ethnic Leo-Nuer with an Anuak minority population (UNHCR, June 2016). I made an insight on this area by repetitive visits that helped me to identify the research participants. By establishing smooth relations with the concerned bodies in the camp, I have identified five children with disabilities purposefully from age 12 up to 17 who were able to communicate easily. The study was focused on describing their lived experience from their own perspectives.

3.3.Sampling Design

Purposive sampling is a form of non-probability sampling method that entails me to select participants based on a variety of criteria which may include communication skills to express own experience of the disability as a refugee child, and the willingness to participate in the research (Jupp, 2006). So, five children with disability (four were with different physical disability and one with epilepsy) were selected purposefully for this study.

3.4.Data Gathering Tool

In a qualitative study, the primary data collection instrument is the researcher, yet it is also standard procedure of data collection to increase trustworthiness of the data. For this reason unstructured face-to-face interview was used as a method of data generating instrument. In addition, field observation also used to see the current and day to day experiences of the children.

3.4.1. Unstructured Interview

Data is collected through the use of unstructured face-to-face interviews. I adjusted the interview plan according to each participant's needs to allow for an unlimited opportunity of self-expression (De Vos, Delport, Fouche & Strydom, 2011). The unstructured interviews were focused on the central research question which is the lived experiences of refugee children with disabilities. In this way, in line with phenomenological research, the interview placed the respondents as an active participant and expert in their own life, validating their knowledge and contribution to the research process (Gill & Liamputtong, 2009).

In fact, my research participants are from South Sudanese Nuer tribe, I used interpreter during the interview. He is a member of the refugee and serves the camp as a social worker,

interpret meetings and different occasions from Nuer language to English and I provide him a short training about interviewing, and ethics during translation for research in general.

I interviewed the participants twice in different time. The issues raised in the second interview were mainly emerged from their first interview responses. At the beginning of both interview sessions, the major central question were asked and different emerged questions (appendix A) were raised during the interview and the issues for one respondent raised differs from the other because each specific items are raised for them based on the subjective issues and life experience they speak.

3.4.2. Observation Field Notes

In order to capture the day to day life experiences of children with disabilities in their real environment, field observation were made within the refugee camp while children are engaged in different situations. This observation field notes contributed on the description of the lived experiences of children with disabilities who are living in refugee camp. I made direct observation of children with disabilities' actions and situations. According to Creswell (2009), observations are those in which the researcher takes field notes on the behavior and activity of individuals at the research site. In these field notes, I recorded the activities at the research site in a semi-structured way. The observation was conducted in two different days in the refugee camp on 21/03/2009 E.C. and for the second time on 24/06/2009 E.C. These repeated observation field notes contributed for saturation of the data.

3.5.Procedures to Collect Data

I went to the refugee by fulfilling all the permission criteria from the national ARRA agency in Addis Ababa up to the camp field office to inter to the camp and started searching

children with disabilities. I met with ARRA (National Intelligence and Security Service Administration for Refugee-Returnee Affairs) and RADO (Rehabilitation and Development Organization) coordinators in the camp.

After creating smooth relations and consent with them, they gave me member of the refugee who is a social worker and interpreter in the camp. He is from Nuer ethnic group which is the majority of the camp population, and has better experience in interpreting from Nuer to English for all the camp personnel and for strangers like me. After establishing relationship with the interpreter I explained the purpose of the study and encouraged him to bring me children with any kinds of disabilities who are above age 12 and who have ability to communicate.

The interpreter brought 8 children with different disabilities but three of them were extremely shy and refused to interact and communicate with us. So I took five of them for this study purposes. Then the interpreter took me to their parents for getting their permission. After I clarify the purpose of the study the parents became voluntary and allowed me to made contact with their children. For children who were separated from their parent, the consent was made with ARRA field coordinator. I established rapport and smooth relations with them, and they showed their willingness to participate in the study and promised to come and contribute until the end of this study. The interviews were held at Jewi refugee camp zone A; in ARRA field office and convenient time to make the interview were decided by the participants.

Regarding the observational field notes, each child with disabilities in the study was observed in different settings. In order to minimize the children's expectations of being observed that minimizes their real behavior, I went to their environment just as a rough visit of the schools they are learning and their home but I have informed the social worker as well as the ARRA coordinator so that they allow me to visit and take the field note.

3.6. Method of Data Analysis

The data collected were analyzed using thematic analysis. It is a flexible way of description of phenomena from sets of data from the interview as well as observational field notes and allows for thick descriptions to emerge (Braun & Clarke, 2006). Due to the exploratory and descriptive nature of the study, this approach is suitable as the aim was to explore and describe on participants' experiences as they are a child with disability in refugee camp. I followed Braun and Clarke's (2006) step-by-step guideline to discover themes pertinent to the research question.

The interview records were transcribed verbatim. I used the process of systematically searching and arranging data from the observation and the interview transcripts that I accumulated by reading as well as listening to the tape. Through repeated readings, I was able to find themes and patterns. Specifically, I searched for certain words, phrase or patterns that were repeatedly presented as I studied the transcripts. In this process I color-code and underline interesting passages which will then grouped together in categories. I then began to develop my own theme to put data into categories to help me analyze and sort the data (Robert, 2011; Padgett, 2008).

Accordingly I identified four major themes such as: 1. Refugee camps as a survival for life, 2. Views of children with disability on nature of their disability, 3.Challenges and obstacles within refugee camp and 4. Outcomes of refugee members' observation and feelings on the life of children with disabilities. And under each major theme there are categories of sub themes and the descriptions of the findings both from the interview and observational field notes are incorporated simultaneously which are discussed in chapter four. In order to minimize personal

views and biases, bracketing and phenomenological reduction was made before and during the analysis.

3.6.1. Braun, V. & Clarke, V. (2006). Step-by-Step Thematic Analysis Procedures

The process starts when the analyst begins to notice, and look for, patterns of meaning and issues of potential interest in the data, this may be during data collection. The endpoint is the reporting of the content and meaning of patterns (themes) in the data. Analysis involves a constant moving back and forward between the entire data set, the coded extracts of data that you are analyzing, and the analysis of the data that you are producing. Therefore, writing should begin in phase one, with the jotting down of ideas and potential coding schemes, and continue right through the entire coding/analysis process. Analysis is not a *linear* process where you simply move from one phase to the next. Instead, it is more *recursive* process, where you move back and forth as needed, throughout the phases (Braun, & Clarke, 2006). Table 1 contains the summary of steps in thematic analysis.

Table 1. Summary of the Braun, & Clarke (2006) step-by-step thematic analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic „map" of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

3.7.Ethical Consideration

The study was conducted after getting support letter from Addis Ababa University to ARRA head office (National Intelligence and Security Service Administration for Refugee-Returnee Affairs). The head office also gave me a support letter to its sub- office in Gambella town and I followed each of their procedural process to visit the refugee camp because the security process needs patience in order to begin the study. Then informed consent was obtained from study participant as well as their parents to confirm willingness for participation after explaining the objective of the study. I also assured to the respondents that the information gathered had never used for other purpose rather than the consumption for this study only. The respondents were notified that they have the right to refuse or terminate at any point of the interview. The information provided by each respondent was kept confidential and pseudonyms were used in this regard. Voice recorder also used after getting their permission to record.

CHAPTER FOUR

FINDING

This phenomenological study was guided by Braun and Clarke's (2006) step-by-step guideline to discover the major and sub-themes pertinent to the major research question. Primarily, the general backgrounds of participants were presented below including brief description of their background in a table, then; the experience is presented in commonly identified general and sub themes that were elicited from interviews and field observations with the participants. The results are a description of the lived experience of being a child with disability in refugee camp. A table is included to enhance the clarity of the identified major themes and sub-themes. The participants' names have been changed and pseudonyms were used to maintain anonymity and confidentiality for the participants.

4.1.Demographic Backgrounds of the Research Participants

All the participants are South Sudanese refugee children with disabilities who are between age 12 and 17 and now sheltered in Jewi refugee camp which is found Ethiopia; Gambella regional state. Four of the participants are living with different categories of physical impairment and the rest one participant experiences epilepsy.

Here, table 2 contains the pseudonyms of the research participants, their sex, age educational background, the type and onsets of their disability, family status and their location in the refugee camps are depicted in table 2 below:

Table 2. Background of the participants

Participants' Pseudonym	**Sex**	**Age**	**Education**	**Type of Impairment**	**Onset**	**Family status**	**Location** Jewi Refugee camp:
1.Gatlat James	M	16	5th Grade	Physical impairment (left hip dislocation) so, he uses stick for walking.	At age 5	Both alive (but very old)	Zone B
2.Dak Majuan	M	13	2nd Grade	Physical impairment (Club foot)	Congenital	Lost his father &lives with mother	Zone C
3.Nyalwal Gach	F	14	Uneducated	Epilepsy	At age 4	Lost her father &lives with mother	Zone B
4.Gtluak Both	M	13	2nd Grade	Physical impairment (polio, use wheelchair to move)	At age 4	Both alive	Zone A
5.Nyawich Kun	F	16	3rd Grade	Physical imp.(Spinal cord deficiency called scoliosis)	At age 6	Has no family in the refugee	Zone B

As table 2 indicated, three of the participants were male and the rest two were females. They are also within age range of 13-16. Except the 3rd participant, the other experienced schooling and enrolled in different schools of the refugee camp. Table 2 also showed that the 3rd participant experienced epilepsy and the other four participants are living with different types of physical disabilities. Some live in zone A, some are from zone B and Zone C of Jewi refugee camp.

4.2. Themes

As it is indicated in the method section, the unstructured face-to-face interviews and field observations were made twice in different time for the purpose of saturation (to get reliable data). Here, after repeated review of the transcribed verbatim of both interviews and observation field notes, the lived experiences of children with disabilities are presented below in major and sub-themes.

The following table 3 contains the major themes emerged from the transcribed data of each participants. Totally four main themes with several sub themes are identified and described below.

Table 3.Major and sub themes of the finding

No	Themes	Sub Themes
1	Refugee camps as a survival for life	a. Refugee camp benefits to stay alive. b. Accessibility and support
2	Views of children with disability on nature of their disability	a. Type and Causes of disability b. Struggles to cure the disability
3	Challenges and obstacles within refugee camp	a. Challenges and obstacles related with social and physical environment of the refugee camp b. Facing Parent related challenges in Refugee camp c. Experience of Prejudice and discrimination towards children with disability in Refugee camp
4	Outcomes of Refugee members' Observation and Feelings on the Life of Children with Disabilities	

4.2.1. Theme 1. Refugee camps as a survival for life

This first theme of the finding indicates that refugee camp has played a role for the survival of children with disability. The refugee camp helped them to at least stay alive. Under this section the description includes the role of refugee camp in saving their life and the support and accessibilities of the camp for children with disabilities are presented.

4.2.1.1.Refugee camp benefits to stay alive.

As a result of lack of sustainable peace and security in South Sudan, many are dying; their lives are struggling with the scarcity of food and absence of basic livelihood supplies in different

villages of South Sudan. In spite of these, children with disabilities who are joining refugee are at least saved in life; they can access food rations from the refugee camp. Even this time, still there are conflicts in the country South Sudan and the provision of humanitarian support is almost empty because of the conflict. But in Jewi refugee camp, children with disabilities are living without the sound of bullet. If they were in South Sudan, they could die by the conflict or hunger because access to aid and several type of support is unthinkable.

Even children with disabilities suffer a lot during traveling from the conflict affected area of South Sudan to the survival refugee camps that are found in Ethiopia. They passed several ups and downs until they joined refugee camps. To this point, Dak (a child with clubfoot) has passed unforgettable memories through his journey:

> *The way we reach to the land of Ethiopia was very sickening… I escape with my mother and many other South Sudanese. I was repeatedly left behind and it is very difficult to express the feeling to become at the end of escaping peoples. it was my mother who wait me because I cannot walk and run equally with others because of my disability, when I left behind I become feared a lot, my mother also highly strained because the war was going near distance behind us but after a lot of stress we reached the UN cars. We are now living in peace in this refugee camp, there is no conflict in this camp.*

Children with disabilities in the refugee camp could die if they were in South Sudan. The condition found there is very terrible for living; children with disabilities used the statement that refugee camp saved their life. Their arrival to the camp helped them for better survival. The soldiers could kill these children if they were in the conflict zone because there were high

exchanges of gun firing and children with disabilities cannot escape equally with other people because of their disability.

4.2.1.2. Accessibility and support

The data from in-depth interview and observational field note supported that children with disabilities can access some sort of support from the refugee camp. Even though the amount and type of supports they received from the refugee are not equivalent up to the children' expectations, they can receive supports such as learning equipments (for those who are enrolled to school), rehabilitation aids like wheelchair, food supplies; here food rations are distributed for the refugee members based on the quota of the family members. Each parent receives foods based on the number of children or members of the family.

There are also clinics within the refugee that provides medical supports for the refugees at large and children with disabilities in particular. Nyalwal Gach receives a tablet that minimizes her epileptic seizure from the clinic but sometimes the clinic may face shortage of medicine then children with disability may suffer until the clinic bring it again. Children with disabilities such as Gatluak also received wheelchair from the refugee. RADO (Rehabilitation and Development Organization) provides physical rehabilitation services to them. The services include providing wheelchair for children with physical disability, crunches and other walking sticks for person with disabilities, a physiotherapy services for person with disabilities at large and children with disabilities who need the services in particular.

Regarding accessibility issues, the observational field notes and the face to face interview revealed that at least one of the rooms in any social service provider buildings in the refugee camp has ramps, and parallel bars for walking. Children with severe physical impairment can

access a wheelchair, students who use wheelchair can easily inter to class. This situation, in one way or the other, initiated and support children with disabilities for learning. Furthermore, Gatluak (the child with physical impairment who uses wheelchair) described as:

> *Even to go refugee school also it is possible for me by RADO, it is RADO which gave me this wheelchair, you know… if RADO would not gave me this wheelchair I planned to stop learning because this refugee camp, especially afternoon, its weather become very hot, so it is very painful for me to go with my hand. You know… before RADO provided me this wheelchair, I was always walk with my hand and knee, I was walking with four limbs like a baby; still I remember how the sand burned my hand. But now really thanks for RADO they gave me this wheelchair and I am very happy and I can easily enter to the clinic, classroom and RADO centers sitting on my wheelchair because at least one of these buildings has a flat way up to the entrance door* (…to indicate ramp)…

The field note also revealed that even though there are some obstacles around home, children with disabilities can use the toilets and bathing room, it is accessible for wheelchair user, but during rainfall the area from home to toilet and vice versa become muddy and challenge children with physical disabilities. Data from the observation also showed that the school physical environment such as the gets of classrooms and school toilets have ramps and easily accessible for wheelchair users.

Even though children with disabilities in the refugee camp experience challenges streamed from their disability, they consider themselves as lucky and blessed for joining the refugee schools. Except Nyalwal Gach (the child with epilepsy), the rest participants are learning in the refugee schools so that they are happy to be in school. It is the moves through schools that

make their future brighter. For reasons that are presented in the third themes, Nalwal is not still in the school. Being out of school for having disability is not fair especially for children with disability who experiences several obstacles in their life.

4.2.2. Theme 2. Views of children with disability on nature of their disability

The views of children with disabilities who are living in refugee camp about the nature, cause and treatment of their disabilities are different and each of the situations are described below in the identified sub-themes.

4.2.2.1. Type and Causes of disability

These children experienced different disabilities but it can be stated in two broad categories; different types of physical disability and the second is epilepsy. Nyalwal Gach is living with epilepsy, at least twice a week she experience the seizure and the rest four experiences different types of physical disabilities. Gatlat is one of the children with physical disability, his problem is left hip dislocation, as a result his left leg is not functioning and he used a stick for walking. The other child; Dak Majuan is a child with clubfoot. Gatluak is impaired because of polio and he uses wheelchair for mobility. Nyawich Kun is a child who experiences a severe spine malformation which is called scoliosis.

Regarding the views of children with disabilities on the causes of their disability, they have different expressions and understandings on how they became impaired and I have identified three different views that are considered as disability causing issues: bad spirits such as exposure to evil eye person, disability can also be caused by disease and God can also make

someone disabled. And most of them have adventitious disability. Except Dac Majuan, a child with club foot, the other children experience the disability sometimes after birth.

The conditions aggravate as a result of lack of proper care, medication and follow up. Their views on the nature of their disability indicate that they are in the beliefs of traditional and medical model of disability.

For instance, Gatlat said that the only one who is responsible as a cause for his disability is a woman with evil eyes. The evil eyed woman in their village saw him while he was playing in the rainfall. At that moment she saw him when he was in a better and happy situation. After her eye attacked him, he said that the slimy and muddy land immediately slide him and fall down. Then his hip joint broken and missed its position and he was not capable to stand up and walk. Till that time he blames her for the cause of his disability. As a result his families took him to religious place and pray as a treatment from the disability and to run-out the evil eye spirit from him. Dak Majuan (a child with clubfoot) also believed that it is the will of Almighty God for him to be like this. Everybody is made by God so if God made him like this, no one have power to change, in this case he said that he should accept the disability.

Regarding the causes of her disability, Nyalwal (the child with epilepsy) expressed that her condition begun when she was around age four and it is the "bad spirit" that convulses her on the ground. On the other hand, Gatluak (the child with physical disability) believed that he is in this condition because of the polio disease. While he was around age 4 he was seriously sick and became physically disabled. He replied:

> *During that time when disease was not occurred, you know… my two legs were normal, I remember that time in South Sudan how I was playing with neighboring friends. While I*

was happy, disease came and…Oh… makes me like this… I was sick seriously but I cannot get medication. Then after some weeks it minimizes my lower tissue and my leg becomes thinner and thinner, now I have no tissue on my leg and I can't wave my knee.

Nyawich Kun has a spine deformity called scoliosis. She also said that disease affected her backbone and deforms her shape, and she still experiences some pain on her back, chest and joints. She said:

I became disabled and developed this condition when I was 6 years old. While South Sudan was in trouble, I was in hospital at Juba for my treatment because I was sick badly on my backbone and chest, while we arrived at hospital; my upper body has already started the shape that I have now. I do always have a pain in my back, joint and chest. I go to school with my pain but the pain stay silent sometimes. Some says my condition is a bone TB, but the refugee nurses call it scoliosis.

Generally, Gatlat, Dak, and Nyalwal view supernatural powers and divine as the causes for their disability. They believed their impairment is, in one way or the other, caused by other powers such as evil eyes, bad spirit or the Almighty God, while Gatluak and Nyawich believed that it is diseases that lead them to disability; these views are related with some models of disabilities like traditional and medical models.

4.2.2.2. Struggle to treat the disability

In these regards, several struggles are tried in traditional ways of treatment to cure the disability of these children. Children with disabilities described that their parents tried a lot of things to treat/ cure the impairment. The majority used traditional ways in order to cure the disability. Their families' struggle laid towards evicting out the disability causing bad spirit, they

took their children to witch doctors, traditional healers as well as to church pastors to pray for the children.

Gatlat described that his families tried a lot to cure him from the impairment: hip dislocation; they took him to witch doctors and traditional knowledgeable persons who had ability to cure from evil eyes. He also added that his family took him to traditional joint and bone healers and health centers. In spite of all these great effort that aims to bring miraculous change on their disability, nothing was happened and still the children are living with their disability. Gatlat said: "We have tried many ways but I hadn't seen any changes. In this refugee camp also I always attend several religious conferences and all the time they pray for me. But until now, I did not throw my stick." Nyalwal Gach also expressed that she is living with the epilepsy for many years and her parents tried traditional medicines to cure her from it but she still convulse by the epilepsy. She said:

> *My family tried traditional medicine to cure me but the problem did not stop. At least twice a week I fall down and the bad spirit shake me on the ground. When I convulse due to the epilepsy and make different things on the ground, like tremble, they pick some sticks and bit me, they bit me even after I wake up, and they did this because they believed that some bad spirit is convulsing me so they are biting to whisk away the bad spirit from my body. But it is me in the pain…*

The environmental situations occurred in South Sudan become challenging for them to get better medical treatment for at least to alleviate the effects of the infection. The long term displacement as a result of War, and absence of peace in their villages prevented them to get

appropriate treatment, and these displacements due to insecurity aggravated the minor infection and treatable impairment in to a permanent disability. Gatluak explained:

> *Our village was in war and I do not get good medication. The disability first start as a disease when I was around age 4, I was sick seriously but I didn't get better health support because during that time there was no way to go far in South Sudan, everybody fear the war, The cultural medicine that my parent tried did not work and failed to cure me.*

Nyawich also said that she was in hospital at Juba (the capital of South Sudan) with her mother while the war outbreak. She went to the hospital after her mother realized her child's disability is getting serious because Nyawich said that her backbone shape was already deformed and she experience serious pain at her chest and spine. She described:

> *While I was waiting checkup in the hospital, the soldiers were approaching to us and we saw that they were killing everyone on their ways so we immediately leaved the hospital and run away. When the war getting serious in all of our villages, we are forced to leave our homeland, till that time I do not get better treatment and that disease became more serious and turn into a disability like this, because I did not get medication and we were escaping from the trouble which was occurred in our village.*

All these mentioned situations intensify their minor stage obstacles in to the development of a more serious disabilities and the major reason that prevent their struggles were absence of sustainable peace in their country to have medical support and their traditional meaning given to disability.

4.2.3.Theme 3. Challenges and Obstacles within Refugee Camp

Children with disabilities experienced several challenges and obstacles and they face these impediments within refugee camp because of their disability. These obstacles and challenges are described below in different sub-themes.

4.2.3.1. Challenges and obstacles related with social and physical environment of the refugee camp

Children with disabilities who are living in Jewi refugee camp faced diverse challenges that are specifically rooted from being living with a disability. The refugee environment had created several barriers in their life, and they said that they are facing these barriers as a result of their disabilities. Living in the refugee camp with disabilities is very challenging. For example, data from the field observation indicated that people who are looking these children on the refugee street saw them back again and again. Their eyes lied on the affected body. Simultaneously, the interview data indicated that these prejudice and discriminatory looking disturbed the emotions of children with disability.

Data from observation also revealed that the weather condition, the construction of road in the camp for children with physical disability, some part of the refugee population created an obstacle and problem in the life of children with disabilities. For instance, the refugee camp has hot weather so children with physical disabilities who are using wheelchair are feeling discomfort while sitting on their wheelchair for long time especially during afternoon they sweated too much.

The road constructions that connect different zones and institutions within the refugee camp created some obstructions for wheelchair users because the speed breaks constructed within some intervals of the road hinder the movement of wheelchair. For instance Gatluak explained that he was seriously challenged for walking to school because before RADO gave him the wheelchair, he used his four limbs for movement and the hot weather and the ground sand burned him. He told me his experience that during rainfall time in most case he missed classes because he said that if he went to school, his cloth became full of flood water and wet. So, when he arrived at class his chair became wet and children laugh at him, he also added that he felt cold until his cloths get dried. But now RADO gave a wheelchair. If RADO would not gave him, he planned to stop learning because this refugee especially after school at lunch time is very hot, so it is very painful to go with his hand. The sand pilled his hand and still he has the scar sign in his hand. Gatluak remarked:

> *…but still during sunny and hot weather sitting on wheelchair for longer time burned my back and I get sweated a lot, again during rain time moving from one place to the other is very difficult for me because the wheelchair accumulates mud and I cannot push it. Another thing is I am using the main road within the refugee and I am facing two problems that is, in order to minimize car accidents the main road within the refugee camp has blocks (…* to indicate speed breaks*) with some short intervals and these blocks sometimes move-back and stuck my wheelchair, and the other thing is when cars are coming to my direction it covers me with sandy dusts and at night it burns my eyes. I cannot use the side lane because it is not flat and straight, there are also several small ditches and trees that block my wheelchair.*

In addition to these, children with disability suffer from walking long distances to schools. The refugee camp settlement is grouped with different zones which begun from zone A up to zone D, and the level of schools within these zones varies. For instance Gatlat Jems lives in Zone B of the refugee but this zone contains only primary school level (up to grade 4) and Gatlat is a fifth grader, so he attends his education in Zone A which is almost three kilometer from zone B. In this case he is facing a big challenges walking by using stick from home to school and back to home. He described:

> *As you see the weather in this refugee camp, it is very hot, so to go to school and home, really it is very difficult for me. I love my school that is why I walk with my painful disability and with this hot climate. I am not able to walk without stick; I can't go fast like my friends. You know, sometimes I fall down badly because my stick may slip when I walk on flat stone and during rainy time; while I am falling, some children, instead of helping me to stand, they laugh at me.*

Children with disabilities in refugee schools did not received specific attentions and other additional educational support that aimed to minimize the disability effects. If they absent from the refugee school for minor cases, the school did not gave it much emphasis for such conditions, and there is no responsible person that specifically takeout the tasks related with children with disabilities in these schools.

Furthermore, parents of children with disability overly protect their children with disabilities to keep their child from dangers but their actions influence the children' day to day life. Nyalwal Gach said that her family did not let her to school as well as play. Her mother

thought that if she let her to school, she may convulse somewhere and injured. They have also wrong awareness about the nature of the disability that the children experiences. She said:

> *When I speak about school for my mom, she bit me and barks at me, insult me as I am stupid and said 'how do you learn? You disturb the school; you don't know anything even to come back to home so, stop such question, you may convulse in class and I don't want the school to be troubled because of you.' This is the way my mother is treating me.*

She also said that her mother is not right because she want to go school for learning, not for disturbing. The other reason that leads her mother to decide such decision is, as Nyalwal described, there was a teacher in the camp and he informed her mother that her daughter is abnormal and the best solution is keeping her at home. Nyalwal illustrated:

> *…there is a teacher that tells my family not to send me to school because of my behavior. He believes that I am mentally abnormal. He told to my mother 'if she goes to school and if children laugh and abuse her she may throw stone to them and injure, she will become a big trouble for the refugee school and she is abnormal. So it is good to keep her at home' they do not at least try to understand me.*

She also said that they did not allow her to go for playing. She said that they fear if she convulse and fall down somewhere. She told me that there are some children who insult her with no reason, so Nyalwal will not keep silent, she throw stone and may injure them. She said that those children's parent came and told to her mother that it is her child (Nyalwal) who injures their children, Nyalwal said "my mother immediately find stick to punish me, she never let me to reason out."

The other challenges and obstacle that children with disability are facing is delay of food and other aids. Sometimes basic aids such as foods may delay, which is very difficult to survive, In addition to the interview data, the field observation also showed that in the refugee camp other children without disability may find ways to feed themselves, they fetch water or serve cafes and small restaurants around the refugee and received some money but children with disabilities stay at their home and experience hunger. Even if children with disabilities have specific and unique needs, they do not receive specific need based support. It is only RADO which provides physical rehabilitation supports for person with disabilities in general. Dak Majuan (the child with clubfoot) said that he is living with challenges in the camp and he pointed out that from many organizations working in the refugee no one has asked him to at least to buy him shoes, so he is walking barefoot.

4.2.3.2. Facing Parent related challenges in Refugee camp

For children with disability in refugee camp, it is impossible to replace parents and their roles. Parents are everything for their children but there are children entirely alone in the camp, there are also children whose parents are very old or lost one of their parents. These situations hinder the daily lives of children with disability. These children experienced several situations related with their parents. Gatlat said that he has been facing different challenges as a result of his disability, in addition to this; both his mother and father is oldster. He explained that because of their age, financial obstacles are happen in the family's' home; they cannot work for additional income to cover shortage of meals so that the family sometimes exposed to hunger if the refugee food ration became delayed.

Children with disabilities also extremely suffer from the punishment and wrong protections of their family. Children develop multidimensional problems rooted from their parent. Nyalwal in this regard, faced serious problem from her mother. She said that her mother always barks at her and even she beat her with sticks, and her mother did not allow her to go school or to play. For such reason, these children with disabilities are not really happy in their day to day life, because they had no the exposure to play or learn. It is the family's pressure and fear of the social isolation that forced the children to stay at home. Nyalwal said:

> *My mother did not want me to go and learn in school, when I speak about school for my mom, she bit me and barks at me, insult me as I am stupid and said 'how do you learn? You disturb the school; you don't know anything even to come back to home so, stop such question, you may convulse in class and I don't want the school to be troubled because of you.' Beating me is my mother's sign of calling me, she slap me for minor cases. She underestimates me. At this moment I think to make suicide but I know it is not good solution. I want to play in the school; but they do not at least try to understand me. All these abuses and my family punishment make me to feel angry, and I hate to live but I have no any other option. If my father was alive I hope he would take me to big hospital and I would become normal but he is dead. No one loves me in this camp, It is the God's will that one day I will be cured and go to school and play like my normal friends.*

There are also parents who did not accept the disability of their children and tried several but unrealistic ways to cure the disability. When their ways fail to bring visible changes they experience deep sorrow, stress and even crying. This situation of parents became a source of barrier for their children with disabilities. There are also children who completely live alone within refugee camps. Separated from parents and being disabled makes the burden more

difficult. As a child with disability, it is not easy to live alone in refugee camp. Children lost their parents during the travel or they may be killed by the war. Nyawich described that she lost her mother in the middle of South Sudanese village during the trouble. She didn't know whether her mother is alive or not due to this she always felt sad. She said that they lost each other during the run and absconds from south Sudan. Nyawich explained the situation as:

> *You know… being alone as a child is very hard and affect my day to day life. Really I face many challenges, being alone in refugee camp is really painful specially losing your mother makes you sick. When something happen or heard in the camp other children hug their family, but I am alone, I have no one to care for me… If my mother was with me in this camp, I would be happy, she will protect and care for me, My pain is not only my spinal cord disease but I also lost my families it is also another pain for me. If I become sick of malaria or any other conditions in this refugee, I walk to refugee clinic alone but others came with their family and speak for them. During this, I feel loneliness…*

So losing parents in refugee camp is painful. As a result children with disabilities who lost their family in the camp suffer a lot. It affects their social, environmental and other aspects of their life.

4.2.3.3. Experience of Prejudice and discrimination towards children with disability in Refugee camp

Children with disabilities faced different types of exclusionary situations in the camp as a result of their disability. Because of their disability peoples in the refugee showed them several actions that contain negative messages. I also observed that children without disability also demonstrate unreasonable fear when they saw them. The children focused on the disfigurement,

they react differently when they see the affected body. This phenomenon maximizes the children with disabilities' perception on their body images. Within the refugee camp, When other small children see while children with disability (physical impairment) walking on the street, they display fear and if they were playing, they stop it; and if they are walking or playing at distance from their mom/parent, and if suddenly see them coming, they run and hold their mothers dress. This condition is really painful for children with disabilities.

Some children with disabilities had additional nick name which depends on the function and nature of their disability. It is the refugee community who used these names to identify those children. These also interfere with the child's body image and self esteem.

They are facing such discriminatory behaviors. There are some children in the school also who beat or push them and then ran just for fun because they recognized that these children with physical disability cannot run to catch them. Dak Majuan (the child with clubfoot) also described that he is facing several negative attitudes from others in the refugee camp. Children insult him, abuse him. He remarked that when he goes to school, in the time of rest/break, there are someone who abuse him as, why you are walking like this, what kind of disability is yours… etc. But he said that he did not use any reply to them because he knew that it is not him that invited this kind of disability, it is God but he feel it inside even he cry a lot when he became alone, Sometimes older children call him "the slowest and dawdling". He also presented another experiences in a very sad manner; he said:

> *They say me 'when others who can run died, how you escape. It is a miracle!' The camp peoples turn their head to see me in the camp street. As you see, … many people are living in this camp, when I walk and pass those who came from opposite direction, they*

turn their head back to see my walking, and their face is smiling at me, which is I do not like.

Children with disabilities in the refugee camp also faced several discriminatory reactions as a result of their disorder. These discriminatory reactions are not specific in school compound; rather they face it in different place including their home. Nyalwal (the child with epilepsy) explained that people in the refugee including her mother consider her as abnormal, they stigmatize and insult her. She described:

They consider me as a fool, and stupid. I can't go with friends to play, if I move from home for playing, I do not find the children they change their place or back to their home, they don't want playing with me. Within many children, really being alone and playing alone is very terrible. My mother is very serious and angry when I left our home. The children's families also consider me as abnormal. They also said 'why not you are going to die…! because you are abusing our children.' But it is their children who abuse me. Our neighbors in this camp also do not want to see me, they dislike me, they direct talk to me as 'why you are not going to die!' They said this because they judged that I am abnormal so that I am bad for their children, so they don't want their children to play with me.

When someone makes conversations with them, their intension became on the children' disabled leg, body parts or wheelchair which is a sign of disfigurement that lead children with disability to worry about their body images and as a result, these children with physical disabilities experienced negative body images, felt stressed and sometimes stutter while talking. Gatluak (the child with physical disability) added that some children in the school and on the

street of the refugee abuse him, he explained that they said him "why do you come to school because you are disabled, you should stay home". He described with saddening situation as:

> *Especially I do not forget the word one young refugee man said to me 'look God's did! I lost my brother in South Sudan while he was gentle but look this child, he is disabled; but he is not dead and passes those bullet fires of the war. He is very lucky.' This is what I hear but they may say me more than this. I am alive because of God's will and my families' struggle.*

As Gatluak described, some persons in the refugee saw him in different way that makes him to feel discomfort. Nyawich Kun (a child with spinal cord deficiency/scoliosis) also said that some new people may look at her differently and speak each other with low voice and I (the researcher) also observed this situation while she was around water pump queue. After looking her, their facial shape also changed and begun to whisper. They emphasized on her body shape that makes her to feel shame and stressed, she said that she did not respond. Because she said " if I quarrel, no one defend for me, if I reply and argue, I have no mother or father in this camp and no one can look after me."

4.2.4. Theme 4,Outcomes of Refugee Members Observation and Feelings on the Life of Children with Disabilities

Others' discriminatory attitude and responses as well as the barriers in which children with disabilities are facing disturb their day to day life and affect their feeling and emotions. These children with disabilities develop stress and low self image because of the prejudice and discrimination they are facing in the refugee camp.

For instance, Gatlat (a child with hip dislocation) described that because of things that he faced in the camp as a result of his disability, he saw himself as lacking and weak person. Because of the jocks children made at him based on his disability and other related situations, Gatlat experienced low self esteem and he said: "some children make a fun and ran away because they know that I can't chase them; if I become angry with them while I am disabled it becomes non sense. I do not have anything to do; I cannot fight with them because I am disabled."This implies that children with disabilities develop fear, stress and emotional disturbances which are rooted from the refugee communities' reactions and views of the disability.

Children with disabilities were also very sad and experienced psychological burdens as a result of the challenges they faced in the camp. Others observations influenced their day to day lives. Dak (the child with clubfoot), said:

> *even though some children are seems against me, I did not reply for them back, but when I go to bed or when I become alone I start to feel it, I feel that I am unhealthy, I have no pain or disease now but their bad looking in these camp lead me to stress. I have nothing which is my problem, anyways God did me like this, I do not put in my mind that there is loss in my body because I am made by God I am comfortable I am walking, talking with people, I can write in school but it is others who push me to worry, they look me as having other nature.*

Others' misunderstanding about these children's disability affects their current way of living and future life also. Because of some persons who have incorrect feeling and understanding about nature of disability in general, made children with disabilities to experience

feeling of neglect, low self image and made them to worry about what they lost. Nyalwal (the child with epilepsy) explained:

> *Always in our home I am not feeling well, they always abuse me, they said me stupid, consider me as I don't know everything, when I convulse due to my epilepsy on the ground, they pick some sticks and beat me, they did this because they believed that some bad spirit is convulsing me so they said that they are biting to whisk away the bad spirit from my body. But it is me in the pain, even after one day when I touch my body, I feel that pain from beating; and when they beat me I become angry and feel to kill myself. All their activities disturb me and I hate to live. No one belongs to me. The refugee camp life is really not good for me. I sometimes think to make suicide, but I know it is not good solution.*

It is others misunderstanding, prejudice and discriminations that upset children with disabilities in the refugee camp. Gatluak (the child with physical disability who used wheelchair) described that when other people look his disability while they are making conversation, he feels discomfort, he stressed a lot, and he also explained that sitting on wheelchair during hot weather makes him to fill bad about his disability. He said:

> *When I remember my disability, I always internally feel to stand up and walk. I do not feel good sitting on wheelchair. My life is not good and I am not happy. Some times in deep sleep I dream while I am running and chasing each other with my friends, walking with my normal legs, but when I wake up, I am not like that and there are days that I cried a lot. I do not like to become disabled but I have no ways, so...you know I should accept it (…* he cried*).*

All the social and environmental barriers that children with disabilities experiencing in refugee camp impede their life as well as feelings about themselves became distorted. While observing them on different occasions, other children are preferred to play with their same peers without disability; mostly children with disabilities observe others while playing.

Lack of proper support and the burden from insecurity as well as displacement put children with disabilities in stressful situations. Nyawich (the child with scoliosis/ spine deformity) also said that in addition to her disability, being alone in refugee camp affects her day to day life. She said that the feeling is really painful. When she is in publics peoples are looking her repeatedly which she dislikes and makes her feel stress and discomfort. She also added: “My pain is not only my spinal cord disease but I also lost my families it is also another pain for me.”

CHAPTER FIVE

DISCUSSION

As stated in the preceding chapter, this study would help increase what is known about living in refugee camp as a child with disability and build new knowledge related to the experience of refugee children with disabilities. Thus, the findings of this study were discussed and reviewed according to the emerged major themes with previous studies and relevant literatures. And it starts with the first theme: Refugee camp as a survival of life for children with disabilities.

Refugee camp as a survival of life

The study showed that children with disabilities in the refugee camp receive some services and supports from different organizations who are working collaboratively within the refugee camp. Children with physical disabilities (lower limb dysfunctions) for instance, had received wheelchairs from RADO. Organizations coordinated with UNHCR provide food and other infrastructure to the family of these children. On the other hand, the report of Department for International Development (DFID, 2010) and UNHCR (2005) presented that UNHCR is responsible and took the major roles in protecting refugee populations but there are several international community and organizations working collaboratively in different areas of provisions with UNHCR.

The Geneva declaration (2008) also presented that in areas of conflict societies are vulnerable to several outbreaks of infectious diseases, malnutrition, and diminished access to clean water shelter and a lack of access to basic and obstetric health care. Within these unsecured environment, children, especially children with disabilities are the most vulnerable; in this case

well organized refugee camp that took specified roles like Save the Children, has crucial role in protecting children. This finding also revealed that South Sudanese children with disabilities are happy to be in the refugee camp, after they escape the insecure area, they joined refugee camp and now their life is saved from those highly life strained compounds. Mulugeta (2011) also confirmed on his study that there are different organizations working with UNHCR which provides treatments for people with disability, particularly those with sights and hearing impairment, inviting specialist to the camp, provides rehabilitation equipments including walking crunches and wheelchairs.

In spite of some problems they encounter from peers, many children with disabilities can also learn in refugee schools. They are hopefully happy to be in school. On the same manner, Save the Children (2006) stated that children, specifically children with disabilities have to enroll the early childhood as well as primary school education in the emergency and refugee areas. The report also added that to stimulate and enhance the physical, intellectual, emotional and social development of school age children with disabilities through the provision of adequate schooling sectors working within emergency response areas should jointly work and establish wide opportunities for these children

However, there are also other research findings that show children with disabilities as a primary victim in areas of settlement and refugee camps. Women's Refugee Commission (2014), Rachel (2005), and Eva **(**1997) pointed out that children and adults with disabilities are neglected, and the last to be considered, especially the hidden types of disability such as epilepsy; are tend to be neglected in provisions of services with in refugee camps. In this regard, this study also shows the presence of some challenges faced only by children with disabilities. And it is discussed in the third theme.

Views of children with disability on nature of their disability

In a broader view I have identified two views of children with disabilities in the camp about their nature of disabilities: cultural view which is traditional ways of perceiving disability is the first view that I identified. In this case some children believed that disability were happened to them as a result of supernatural power such as the Almighty God, the evil spirits such as a result of looked by evil eyed person. And the measure they and their family took to "cure" or treat the disability also reflects more of religious viewpoints and traditional healers. Their views about disability in general can lean towards the traditional/ pre- modern model of disability. Scholars such as Beaudry (2016), Marianne (2009), and Tirusew (2005) described that traditionally, in many cultures around the world, people with physical, sensory or mental impairments were thought of as under the spell of witchcraft, possessed by demons, or as penitent sinners, being punished by God for wrong-doing by themselves or their parents.

These writers presented that in many societies early understandings of disability were based on religious fear. People with disability represented the punishment of an angry God. Parents had transgressed or sinned and their child with disability was their "cross to bear". Accordingly, people with disabilities were feared and loathed and were subject to cruel treatment. In my study also children with disabilities who are under this believes blame the evil spirits and "people with evil eyes" for their causes of disability and accept the disability without any preconditions because they believed that it is God's did so they should accept. These children and their families are regularly attending religious prayers within the camp waiting for miraculous relief from the disability.

The second view that I presented is directly related with the medical viewpoints of disability. These children believed that their disability is the result of infectious diseases outbreak during the trouble of their country. They became sick but absence of peace as well as lack of proper medication made them disabled. Instead of rehabilitating them and finding ways on how to live with the disability, the children presented that their families were, even until recent time struggle to "cure' the disability but lack of cure stress the family and the children.

According to Slee (2016), Marianne (2009), and Mirza (2011), the medical model of disability usually focused on the impairment, rather than the needs of the person. The power to change people with disabilities seems to lie with the medical and associated professions, with their talk of cures, normalization and science. The decisions of these professionals affect where people with disabilities go to school; what support they get; where they live; what benefits they are entitled to; whether they can work; and even, at times, whether they are born at all, or allowed to have children themselves.

Challenges and Obstacles within Refugee Camp

Refugee children in general may experience and witness disturbing events or be separated from their family, at the same time, family and other social support networks may be weakened and education may be disrupted. These experiences can have a profound effect on children; particularly children with disabilities are the most vulnerable group (Preedy & Watson, 2010). In addition to this, Beaudry, (2016), Action for the Rights of Children, (n.d.), Lisa, et al. (2013), and Eva, (1997) presented that refugee and displaced children and adolescents with disabilities are at increased risk of abuse and exploitation for a variety of reasons; these may include separation from their families, lack of access to education, failing to get priority during support

provision, and the need to take on adult responsibilities such as caring for siblings. The finding in my study also revealed that children with disabilities faced several challenges in their life journey. Some of them lost their parents and losing parents in the refugee camp became a serious problem for these children and develop a sense of loneliness. Nyawich: the child with spinal cord injury presented the feeling of losing parents in refugee camp and she said:

> *You know… being alone as a child is very hard and affect my day to day life. Really I face many challenges, being alone in refugee camp is really painful and no one understands it; specially losing your mother makes you sick. When something happen or heard in the camp, other children hug their family, but I am alone, I have no one to care for me… If my mother was with me in this camp, I would be happy, she will protect and care for me, My pain is not only my spinal cord disease but I also lost my families it is also another pain for me. If I become sick of malaria or any other conditions in this refugee, I walk to refugee clinic alone but others came with their family and speak for them.* (Personal interview on February 27/2009 E.C.)

The physical environment within the camp such as health centers and other social service providing rooms has ramps and ease the entrance but children with physical disabilities who are using wheelchair are not comfortable with the wheelchair during sunny time because the weather in the refugee area are very hot. The road constructed within the camp hinders their free movements. Other findings such as the State of the World's Children (2013), and Ahlen, (1997) pointed out that children with disabilities are three to four times more likely to be victims of violence. Children and adults with disabilities often face a wide range of physical, social and environmental barriers to full participation in society, including reduced access to health care,

education and other support services. They are also thought to be at extensively greater risk of violence than their peers without disabilities.

Children with disability are often excluded from activities directed at children such as play-groups, pre-school activities and cultural activities. (Eva, 1997). Disability limits access to education and employment, and leads to economic and social exclusion (DFID, 2010). Millions of children have been killed, disabled, left homeless, or separated from their parents, and many have been psychologically traumatized. Children experience many different types of trauma prejudice and discriminations in war and conflict zone as well as in refugee settings (Manitoba Education, 2012; Tamashiro, June 2010). This finding also discovered that children with disability in the refugee camp are experiencing prejudice and discrimination from other members of the refugee. There are exclusionary situations in the camp because of their disabilities. Some children with disability also have nick name rooted it's base on their nature of disability and this practice led them to become stigmatized and develop feelings of stress and low self image.

Outcomes of Refugee members' Observation and Feelings on the Life of Children with Disabilities

Because of the prejudice and discriminations children with disabilities facing in the camp, their life is disturbed and they are experiencing emotional disturbances such as stress, withdrawn behaviors and become sad. Because of some persons who have incorrect feeling and understanding about nature of disability in general, and their actions and responses to children with disabilities in particular made children with disabilities to experience feeling of neglect, low self image and made them to worry about what they lost. It is others misunderstanding, prejudice and discriminations that upset children with disabilities in the refugee camp.

In this regard, Barbara (August 2000) explained that exposure to severe trauma, such as violence and ongoing fear of safety, have lasting negative impacts on the physical and mental health of children that last into adolescence and adulthood, there is also a cumulative outcome in terms of trauma and adversity. That is, the greater number of traumatic or adverse experiences that a child has, the more likely they are to develop a trauma response or develop physical and or mental health difficulties, low self esteem and sometimes develop behavioral disorders.

The repetitive discriminatory responses towards these children also affected interaction with others; some children with disabilities have low feeling for life. These children are facing discriminatory attitude even from their home. In addition to the finding of my study Save the Children (2006) also revealed that these groups of children were identified as vulnerable groups due to discrimination, increased dependency on others, and their extreme vulnerability to the effects of deprivation of a family atmosphere, stress of their family due to disability lead them to feel loneliness and other psychosocial problems.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1.Conclusion

Based on the findings and discussions above, the following conclusions are drawn. Children with disabilities experienced and fear the dispute and insecurity of wars. So it is possible to conclude that refugee camp is better place for children with disabilities to survive. It is very difficult for children with disabilities to run and escape insecurity; as a result refugee camp has a better role for children with disabilities to stay alive. Thus, different organizations working on areas of refugee should strive a lot establish well-structured systems of child protection

The study also revealed that children with disabilities' perceptions towards their disability lie under the views of traditional and medical models. Children with disabilities also experience several challenges in the camp; losing parents, having disability-based nick names, stigmatized as a result of their impairment, are some of the challenges children with disabilities are facing. So it can be concluded that many people within the refugee camp has less awareness about the right nature of disability. The findings also disclose that as a result of their disability children are facing prejudice and an act of discrimination from the refugee population. These situations lead children with disability to experience fear, stress and low self-images.

This study also has limitations in some of its moves and processes. It involved qualitative data collected from one field site and a small sample of respondents. Therefore the findings presented here reflect the views, observations as well as the personal life experiences of these

children filtered through the researcher's subjective lens. To counter this limitation and bolster the applicability of findings, the following attempts were made to triangulate the data: using multiple data collection procedures, providing training for the interpreter about research and interviewing, repeated, face to face interviews were made to have sufficient information and cross-checking emerging thematic insights with academic colleagues and experts external to the research. There was also considerable consistency between interview data and information gathered from informal conversations and field observations with children with disabilities.

Another limitation of the study stems the representativeness of the participants. Therefore findings might not be applicable to all children with disabilities in the refugee camps because the identified major themes are mainly the reflection of individual experiences of these children. Additional research with the rest populations is warranted to verify the applicability of these findings. Finally, the study sample included only children with disabilities between the age of 12 and 18 having personal experience of disability within refugee camp. Future research must therefore strive to include more representation from grassroots persons with disabilities.

6.2.Recommendations

Based on the results obtained and the conclusions drawn from the study, the following recommendations are suggested: In a world of competitive and collaborative economic growth, the best solution for nation is TO LIVE IN PEACEFULL COEXISTANCE and the paramount solution for these children is establishing a country with sustainable peace; No countries with civil war saved their nation. Thus, the following recommendations are forwarded:

- In order to create inclusive refugee community that advocate and appreciate diversity, it is better if refugee camp stake holders provide disability related awareness raising

trainings for community and religious leaders within the refugee camp, for refugee social workers and parents;

- Basic knowledge about disability and promotion of positive attitudes should be included in all kinds of training for different actors in refugee camps. Thereby, it is important to stress that children with disability do not only have medical needs and rights but also social, psychosocial and educational rights;
- In order to reach children with disabilities with food, other necessary items and facilities, good distribution systems need to be established;
- It is recommended to have counseling services within the refugee camp for parents as well as children with disabilities;
- Refugee camp organizations should employ well trained special needs education professionals that can plan and implement inclusion within the refugee school and community at large;
- Schools within refugee camps should design strategies that welcome and address children with disabilities;
- It became very essential if the refugee camp employ/ produce well trained caregivers for orphans and children who are separated from their parents.

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Appendix A

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The objective of this face to face interview is to collect necessary information about the lived experiences of refugee children with disabilities.

The central research question was used to begin the interview because the research utilized unstructured interview, then; emerged items during the interview were noted and asked. Those areas of emerged items are described as interview guide below.

Pseudonym of participant: _____

Date of Interview: _____. Time: from _____ to _____

Place: _____

Interviewer: 1. Belay T. (the researcher) 2. John G. (Interpreter)

Major emerged Interview items during interview with refugee children with disabilities:

1. Background information including type onset and causes of their disability
2. Knowledge and perceptions about their disability
3. Any life experiences in their journey from South Sudan to Ethiopia
4. Life experiences within refugee camp as a child with disability
5. Support systems for children with disabilities in the camp
6. Opportunities and challenges they experience as a child with disability

Appendix B

The Transcribed Interviews of each Participant

Here, after repeated review of the transcribed verbatim of both interviews, their lived experiences are presented below. Hence, repeated and similar ideas from both sessions are merged and the summaries are described below. The transcribed interviews of the participants are presented below in case by case manner.

Participant one: Gatlat James

Gatlat is a 16 years old child with physical disability. His hips became uneven in its position so that he has problem on his left hip. He used a stick for mobility. He is now a 5^{th} grade student and lives in Jewi refugee camp at zone B. In zone B of this refugee there is only first cycle primary school (from grade 1-4), so Gatlat is attending his school at zone A which is almost 3 kilometer from his refugee home. His lived experience gathered through Interview is described below:

Living in refugee camp with disability is not easy. I do face a lot of things in my life; because of the thing that I face in the refugee, I see myself as a lacking and weak and nonsense-person person because I am in unable situation to run, jump and play as my friends. If other children insult me I keep myself from fighting because I cannot run with them to fight and even if they are smaller than me I do not chase them because I cannot run, again I cannot walk without my stick, so I feel non-sense to me and so I do not respond to them because I am disabled. When other small children in the camp see me while I am walking on the street, they fear me and stop playing; if they are walking or playing at distance from their mom, and if suddenly see me coming, they run and hold their mothers dress. This condition is really painful. I am one of their brothers in the camp but they react like this because of my disability.

My father and mother are very old and not educated, they do not work for additional income we always wait for rations from the camp. Because of my disability I do not go far with my age mates to collect firewood. So I am not happy with my disability and all with evil eyes.

In our village when we were in South Sudan there were some women with evil eye. One of this woman with evil eye (Called 'Peeth' in Nuer, pronounced "Pase") make me disabled but I was normal when I was small child around 5 years old. During that time, I was playing in the rainfall. I run with my friends in wet and muddy land in south Sudan. Suddenly the evil eyed woman in our village saw me while I was happy and running. Then I suddenly fall down on the muddy and slimy land but I did not able to stand up. My left hip was not on its position. They carry me to the traditional hillers who have knowledge to cure from evil eyes. My family tried a lot to cure me. They also took me to health centers, traditional bone and joint hillers but I cannot be normal and I am like this. Beginning from that time I hate person with evil eyes because I became disabled because of them. In every religion conference and praying program is prepared in this camp; I went there every time because they pray for me. But until now, I did not throw my stick.

I am grade five student at zone A of this refugee camp. When I go to school some children try to play with me, but there are also others who insult me and try to kick me just for fun at me because they know that I can't chase them because I am disabled, if I become angry with them while I am disabled it becomes non sense. I do not have anything to do, I cannot fight with them because I am disabled and I use big stick even to stand up and walk, so how can I run and fight with them? Then I was just keep silent. This is the way I am living; I go to school and come back home.

I am living in Zone B of the refugee and my school is in Zone A. As you see the weather in this refugee camp, it is very hot, so to go to school and home, really it is very difficult for me. I love my school that is why I walk with my painful disability and with this hot climate. I am not able to walk without stick, I can't go fast like my friend. Sometimes I fall down badly because my stick may slide

when I walk on flat stone and rain time, while I am falling, some children, instead of helping me to stand, they laugh at me, and during this time I really feel loneliness. But I want to learn and try to go to school simply without quarreling with others.

My age mates without disability walk very fast to home and when I see them collecting fire wood for their parent, fetch water and carry some goods for their mother but I can't and I fill angry inside because my mother and father are very old and I can't help them. They are also not educated, they do not work for additional income we always wait for rations from the camp. Because of my disability I do not go far with my age mates to collect firewood. So I am not happy with my disability. My only way to support them is become a good student and after I finish my school I will receive some salary in the refugee and support my family. When I grow up and finish my school I will help my family and the people of my country.

The big benefit to be in this refugee camp is our life is saved. Really here in Jewi refugee camp I can say life is good because if I was in South Sudan I may died by the conflict or lack of food because we are hearing that there is lack of food and many are dying out of hunger there and endless war, but here, at least our life is survived. It is good for me to be here, unless if the ration is not received very soon, if it takes some days, that will be big problem because I have no other option to go somewhere to find other food and I have no ability to go far and collect fire wood because other children go far and accumulate fire wood for their families to sell it. My life is based only on the camp ration; I have no any other support, there were some days in which the ration is delayed and I do not forget those days of hunger, there was a day that I had spent without eating. But our relatives from Terfam refugee camp which is found around Itang brought us food in the next day. It is very bad to lose food at home. If I was not disabled I would go somewhere in the camp to do small jobs like fetching water for tea and food sellers, or collect firewood and then I would sell it to buy foods for me and my family but I cannot do this because of my disability…(feels sad and his eyelids covered with tears).

Participant Two: Dak Majuan

Dak Majuan is a 13 years old child living with a type of physical impairment called Club foot. It is a common birth defect in which his both feet are twisted in to an abnormal position and his legs from the feet up to his knees are bended in some degrees. He is a grade 2 student in zone C primary school. His lived experience gathered through the face to face interview is described below:

My life is really bad because I became clubfoot even my walking is too difficult and different from others, what can I choose because really I become clubfoot that make me disabled person. Now I am in the refugee and I have different challenges from refugee that I know them, live them, even I still walk barefoot on this sand, from all organization in this camp no one asked me to buy shoe. Here, in my life I didn't get everything healthy but only school, every morning I go to my school and I will also join RADO center always for exercise. In RADO offices there are different sport machines for persons like me so I always go to the center and use the machines. In addition to those machines I would hopefully happy if RADO open school for children like me. In the will of God I always go to school earlier. I like my school and the RADO services.

In my life I have been walking slowly, I can't run fast, if I tried my left foot hits the other and I will fall. The way we reach to the land of Ethiopia was very sickening, there was no water, food, we were crossing the bushes of South Sudan and I have no shoes even. So when we reach to the car my leg was wounded and scratched. I escape with my mother and many other South Sudanese. I was repeatedly left behind and it is very difficult to express the feeling to become at the end of escaping peoples. it was my mother who wait me because I cannot walk and run equally with others, when I left behind I become feared a lot, my mother also highly strained because the war was going near distance behind us but after a lot of stress we reached the UN cars. We are now living in peace in this refugee camp, there is no conflict in this camp.

My challenge is my disability because I am not walking like human being who has no clubfoot; I am not walking very fast, so it challenges my life. Every morning I feel to be normal, I feel to walk like persons without club foot. But it is the will of God in my life. If he made me like this, who have power to change.

My father died by the conflict in South Sudan, now I am living with my mother in the refugee and we do not have problem at home but when I am going to school, road, in the time of rest/break, there are someone who abuse me as, why you are walking like this, what kind of disability is yours… but I have no any reply to them because I know that it is not me that gave me this kind of disability it is God so I cannot reply to them or insult them but I feel it inside even I cry a lot when I become alone, my mind repeatedly remember their words.. Sometimes older children call me "the slowest and dawdling". I feel I am not complete because of the disability, I am not feeling good, but if God created me like this, I cannot say anything, I should accept it but if there are any options to correct my leg it can be okay for me but I don't think so, there is no way to change foot. (During this time Dac's eye was surrounded by tears, feeling sad). Peoples abuse me … (…crying). They say me "when others who can run has died, how you escape." The camp peoples turn their head to see me in the camp street. As you see, … many people are living in this camp, when I walk and pass those who came from opposite direction, they turn their head back to see my walking, and their face is smiling at me, which is I do not like.

In my family all have no problem but out of home they abuse me, I feel sad but I do not insult them, I do not reply because it is God which made me like this. While others abuse me, I do always feel having a bad idea because they abuse me, Even though they are like against me, I am not abusing them back, but when I go to bed or when I become alone I start to feel it, I feel that I am unhealthy, I have no pain or disease now but their bad looking in these camp lead me to stress. I have no something which is my problem, anyways God did like this, I do not put in my mind that there is loss

in my body because I am made by God I am comfortable I am walking, talking with people, I can write in school but it is others who push me to worry, they look me as having other nature. But I do not blame because my life is saved in this refuge, what if I was left in south Sudan? I could be died and this time no one would remember me.

Participant Three: Nyalwal Gach

Nyalwal Gach: is a 14 years old child with epilepsy who participated in this study. She is living with her mother in Jewi refugee camp at zone B and she did not enrolled in school yet. Thus, her lived experience gathered through the face to face interview is described below:

I lived with this problem for many years. My mother told me that it was started when I was age 4. When the problem started, my family tried traditional medicine to cure me but the problem did not stop. At least twice a week I fall down and the bad spirit shake me on the ground. When I wake up I remember nothing even I do not remember the way to go home. The refugee camp clinic gives me a tablet to stop the seizure. But sometimes I fall down specially if I finish the tablet; I start to see black things which is dark then convulse me and I fall down and shake, after a while I wake up, it happens to me every day.

Always in our home I am not feeling well, they always abuse me, they said me that I am stupid, consider me as I don't know everything, when I convulse due to my epilepsy and make different things on the ground, like tremble, they pick some sticks and bit me, they bit me even after I wake up, they did this because they believed that some bad spirit is convulsing me so they said that they are biting to whisk away the bad spirit from my body. But it is me in the pain, even after one day when I touch my body, I feel the pain of their biting; and when they bit me I become angry and feel to kill myself, they also call me the stupid, a girl that don't know everything and you are abnormal. All their activities disturb me and I hate to live.

I am not really happy with my parent because they will not let me to school and playing. My mother did not want me to go and learn in school, she thinks that if I can go to school, I may convulse somewhere. But she is not right I always see the get of the school but it is closed for me. When I speak about school for my mom, she bit me and barks at me, insult me as I am stupid and said "how do you learn? You disturb the school; you don't know anything even to come back to home so, stop such question, you may convulse in class and I don't want the school to be troubled because of you". So I always do not care about other things but only about school, I want to go school for learning; I want to play in the school, but there is a teacher that tells my family to not send me to school because of my behavior. He believes that I am mentally abnormal. He told to my mother "If she goes to school and if children laugh and abuse her she may throw stone to them and injure, she will become a big trouble for the refugee school and she is abnormal. So it is good to keep her at home". They do not at least try to understand me. All these abuses and my family punishment make me to feel angry, and I hate to live but I have no any other option this is the reason I walk alone, and play alone.

They also did not allow me to go for playing because I may convulse somewhere or they fear that I do not keep silent when children insult me and say me bad things, I chase them and throw stone. Sometimes I kick their head with stone. I did this because they say me bad words. They stigmatize me. I also run away from home if my mother tries to punish me I collect stone to throw, I also angry at her because she did not try to understand me. Biting me is my mother's sign of calling me she slap me for minor cases. She underestimates me. At this moment I think to make suicide but I know it is not good solution.

If another family came to tell her about that is me who chase their children, she find stick to punish me. No one stand belongs to me. They have also other reason to keep me at home; when the seizure falls me down and after my wakeup, I confuse and walk in wrong direction to get to my home, so they believed that I may lost in the forest. The refugee camp life is really not good for me. The

children's families always consider me as abnormal. They also said "why not you are going to die…! because you are abusing our children". But it is their children who abuse me. Our neighbors in this camp also do not want to see me, they dislike me, they direct talk to me as "why you are not going to die!" They said this because they judged that I am abnormal so that I am bad for their children, so they don't want their children to play with me.

I can't go with friends to play, if I move from home for playing, I do not find the children they change their place or back to their home, they don't want playing with me. Within many children, really being alone and playing alone is very terrible. My mother is very serious and angry when I left our home. If my father was alive I hope he would take me to big hospital and I would become normal but he is dead. No one loves me in this camp, I hope my problem may have solution but no one took me to big hospital. It is the God's will that one day I will be cured and go to school and play like my normal friends. The only thing that I say about this refugee is I am staying in life. To live in life, it is good, because if we were in South Sudan the soldiers may kill us.

Participant Four: Gtluak Both

Gtluak Both: Gatluak is a child with physical impairment he has mobility problem in which he uses wheelchair for mobility. He is 14 years old and learns in Jewi refugee camp zone A primary school at grade 2. The lived experience of Gatluak is presented below:

During the time when disease was not occurred, my two legs were normal, I remember that time in South Sudan how I was running and playing with neighboring friends. While I was happy, disease came and makes me like this, because it was very difficult to go to big hospital in lack of peace. So, our village was in war and I do not get good medication. The disability first start as a disease when I was around age 4, I was sick seriously but I didn't get better health support because during that time there was no way to go far in South Sudan, everybody fear the war, The cultural medicine that my parent tried did not work and failed to cure me. Then after some weeks it minimizes my lower tissue

and my leg becomes thinner and thinner, now I have no tissue on my leg and I can't wave my knee. The refugee people and nurses told me that my disability is caused by polio.

Today I can't walk as before because I really became disabled, I have no some ability, such as footballs and different playing, I am not able to do as before. Even to go refugee school also it became possible for me by RADO, it is RADO which gave me this wheelchair, if RADO would not gave me this wheelchair I was planning to stop learning because this refugee especially after school at lunch time is very hot, so it is very painful to go with my hand. The sand pilled my hand still I have the sign in my hand.

My feeling in my life is not really good, before RADO provided me this wheelchair, I was always walk with my fingers and my knee, I was walking with four limbs like a baby, still I remember how the sand was burning my hand as you see the land of this refugee is completely sand, especially in the afternoon it becomes very hot and it was very difficult to walk for me, everyone that saw me walking on the hot sandy street they bark at me to stay at home, but I am a child and I want to see the environment, the refugee small market, I want to play and learn, they were right because this area is very hot specially in the afternoon but I was moving. During rainfall I missed many classes at that time because if I went within the rainfall all my clothes were full of flood and the chair that I sit on become watery and until my cloth dries I feel cold in the class so I preferred to stay at home.

But now really thanks for RADO they gave me this wheelchair and I am very happy and I can easily enter to the clinic, classroom and RADO centers while sitting on my wheelchair because at least one of these buildings has a flat way up to the door (to indicate ramp), but still during sunny and hot weather sitting on it longer burn my back and I get sweated a lot, again during rain time moving from one place to the other is very difficult for me because the wheelchair accumulates mud and I cannot push it. Another thing is I am using the main road within the refugee and I am facing two problems that is, in order to minimize car accidents the main road within the refugee camp has blocks (… to

indicate speed breaks) with some short intervals and these blocks sometimes move-back and stuck my wheelchair, and the other thing is when cars are coming to my direction it covers me with sandy dusts and at night it burns my eyes. I cannot use the side lane because it is not flat and straight, there are also several small ditches and trees that block my wheelchair.

You know. I feel stressed and I develop speech problem when to start talking with others because I…, visualize that a person that talks with me is looking my body. They talk to me not by looking my face or you know… not other places, they just look my leg and wheelchair. So to respond for them I sometimes stressed and stutter. When I remember my disability, I always internally feel to stand up and walk. I do not feel good sitting on wheelchair. My life is not good and I am not happy. Some times in deep sleep I dream while I am running and chasing each other with my friends, walking with my normal legs, but when I wake up, I am not like that and there are days that I cried. I do not like to become disabled but I have no ways, so, you know… I should accept it (… cry). Really the feeling of my parent is also very sad because they know me when I was normal, so they feel it and sometimes specially before I had wheelchair, they cry when I came from school within rainfall because that time I walk with my hand and knee. My families took me to the clinic but no change. Even if my families are not happy with my disability and their feeling is very bad, they help me a lot; during toilet, during bath, my school friends also push me to school and I am very happy with them and my schooling is good, I am very happy for being in school. But always I dream to walk by my leg but I can't.

Living with disability is very challenging for me. I was born without disability, it happen to me as a disease, and then I am not happy till that, I am not really having an interest for my life, I am not really happy but not bad because I have good families; they also give me good advice, before years they shower me but now they provide me water and I bath myself because it is my lower part which is paralyzed so I can wash myself now. My little brother and his friends push the wheelchair as you see, because I can't role it by my own all the time, they are helping me a lot. But I face problem out of

home; some children in the school and on the street of the refugee abuse me, they said me "why do you come to school because you are disabled, you should stay home". Especially I do not forget the word one young refugee man said me "look God's did! I lost my brother while he was gentle but look this child he is disabled but he is not dead and passes those bullet fires of the war. He is very lucky." This is what I hear but they may say me more than this. I am alive because of God's will and my families' struggle. For the future I will be a good big person because now I am learning in school.

Participant Five: Nyawich Kun

Nyawich Kun: she is a child with physical impairment which is associated with spinal cord deficiency called scoliosis. Her spine (back bone) is bended seriously so that her upper parts of the body are shortened; her back and chest are forced out. She is 16 years old and a grade 2 student in zone B. Her lived experience gathered through a face to face Interview is presented below:

When South Sudan was in trouble I joined this refugee so that my life is survived. My life experience is full of different challenges that I pass through these times. While South Sudan was in trouble, I was in hospital at Juba for my treatment because I was sick badly on my backbone and chest, while we arrived at hospital; my upper body has already started the shape that I have now. While I was waiting checkup in the hospital, the soldiers were approaching to us and we saw that they were killing everyone on their ways so we immediately leaved the hospital and run away. When the war getting serious in all of our villages, we are forced to leave our homeland, till that time I do not get better treatment and that disease became more serious and turn into a disability like this, because I did not get medication and we were escaping from the trouble which was occurred in our village. (… Feels sad)

I lost my mother in the middle of South Sudanese village during the trouble. I don't know whether she is alive or not (… crying) we lost each other during the run and abscond from south Sudan. One

refugee man told me that my father is living at Youm which is a village in South Sudan but I have no news about my mother.

I can learn follow schooling but challenges are there with me; now I do always have a pain in my back, joint and chest. I go to school with my pain but the pain stay silent sometimes. Some says my condition is a bone TB, but the refugee nurses call it scoliosis. I became disabled and developed this condition when I was 6 years old. Now I am student in Jewi refugee camp and my relationship with the school is ok, I like my school, teachers are good for me, but some new may look at me differently and speak each other with low voice. I didn't respond because if I quarrel, no one defend for me, if I reply and argue, I have no mother or father in this camp and no one can look after me.

In this refugee camp I am living alone, who can understand living alone in refugee camp? I have no words to present my feeling really it is painful (… eyes filled with tears). Just this refugee is very good for survival. If I couldn't come here I may die in the trouble or somewhere. This refugee is really saved my life but being alone as a child is very hard and affect my day to day life. Really I face many challenges, being alone in refugee camp is really painful specially losing your mother makes you sick. When something happen or heard in the camp other children hug their family, but I am alone, I have no one to care for me… If my mother was with me in this camp, I would be happy, she will protect and care for me, If she was here with me, I wouldn't wait a very long line to take food rations because every new eyes are at me they look at me repeatedly, If she was with me it is her to be in the line to take rations, when they look at me I feel that they are looking my body and I feel discomfort. I think if she was with me also, my disease will not make me like this, she would take me to health care and I would be not like this.

My pain is not only my spinal cord disease but I also lost my families it is also another pain for me. If I become sick of malaria or any other conditions in this refugee, I walk to refugee clinic alone but others came with their family and speak for them. During this, I feel loneliness

There is only one man in this refugee camp who was a friend of my father while they were in South Sudan. So this man with his camp friends built a small house for me near his family's shelter. It is him who took me to refugee school and I am in grade 2 now, I remember, I was very happy when I join this refugee school. … I do not know what tomorrow will happen but at least thanks to God I am alive now. But I will be very happy if I meet my family. Until South Sudan becomes ok, this refugee is the only place for me to survive. If somebody supports me, I can learn more and for the future support my country.

Appendix C

Addis Ababa University

College of Education and Behavioral Studies

Department of Special Needs Education

Observation Field Note

This observation field note had contains two major sections: Observation on the physical and social environment of the child. And the field note was taken within the refugee camp setting while children with disabilities were engaged in their own activities.

Pseudonym of participant_____

Type of Impairment _____

Date of observation _____

1. **Field Observation on Services and the Physical Environment of the child:**
    - ❖ Safeness of Roads with in the camp for children with physical disability
    - ❖ Accessibility and of Design of home get , toilet, clinics, schools and other buildings, and outdoors for children with disabilities
    - ❖ Provision of materials specific to disability
    - ❖ Presence of appropriate professionals for children with Disability
2. **Field Observation on the social environment of the child**
    - ❖ Engagement and interactions of children with disabilities around home environment
    - ❖ Play and children with disability in different settings of the refugee camp
    - ❖ Schooling and children with disability