

ASSESSMENT OF PHYSICALLY DISABLED CHILDREN'S FAMILY LIFE: THE  
CASE OF CLUB FOOT CHILDREN AT BLACK LION HOSPITAL, Addis Ababa,  
Ethiopia

By

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**Submitted for Partial Fulfillment of the MSW to Indira Gandhi National Open  
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**November, 2018**

**Addis Ababa, Ethiopia**

## DECLARATION

I hereby declare that the dissertation entitled *ASSESSMENT OF PHYSICALLY DISABLED CHILDREN'S FAMILY LIFE: THE CASE OF CLUB FOOT CHILDREN AT BLACK LION HOSPITAL* submitted by me for the partial fulfillment of the MSW to Indira Gandhi National Open University, (IGNOU) New Delhi is my own original work and has not been submitted earlier, either to IGNOU or to any other institution for the fulfillment of the requirement for any other programme of study. I also declare that no chapter of this manuscript in whole or in part is lifted and incorporated in this report from any earlier work done by me or others.

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## CERTIFICATE

This is to certify that Mrs. Tifsehet Lemma Woldetsadik, student of MSW from Indira Gandhi National Open University, New Delhi was working under my supervision and guidance for her Project work for the course **MSWP-001**. Her project work entitled ASSESSMENT OF PHYSICALLY DISABLED CHILDREN'S FAMILY LIFE: THE CASE OF CLUB FOOT CHILDREN AT BLACK LION HOSPITAL which she is submitting, is her genuine and original work.

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## **ACKNOWLEDGEMENTS**

First of all, I would like to thank God for giving me the strength to finish my thesis. Secondly, my deepest thanks go to my advisor, Ato Mosisa Kejela for his patience and cooperation in providing me constructing comments in conducting this research. Then, I thank all my dear family and friends for their continuous advice, encouragement and support. I would also like extend my appreciation to Black Lion Hospital for allowing me to get information for this research. Finally, I thank all the families who participated in this research.

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## **Acronyms**

<b>ADPD</b>	Acquisition Professional Development Program
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>EFA</b>	Education For All
<b>HIV/AIDS</b>	Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome
<b>ILO</b>	International Labor Organization
<b>LMIC</b>	Lower and Middle-Income Countries
<b>MGD</b>	Millennium Development Goals
<b>MoE</b>	Ministry of Education
<b>MOLSA</b>	Ministry of Labor and Social affairs
<b>PWD</b>	People with Disabilities
<b>SIDA</b>	Swedish International Development Cooperation Agency
<b>TGE</b>	Transitional Government of Ethiopia
<b>TPE</b>	Education and Training Policy
<b>UNICEF</b>	United Nation's International Children's Emergency Fund
<b>UPEC</b>	United Public Employees of California
<b>WHO</b>	World Health Organization
<b>NGO</b>	Non Governmental Organization



## **Abstract**

*There are many studies done on childhood disabilities, but not on the family life of children with physical disabilities in Ethiopia. Therefore, this study aimed to assess the family life of physically disabled children: the case of clubfoot children coming to Black Lion hospital. To achieve the objectives of this study quantitative research approach (descriptive survey) and qualitative research approach (interview) was used. Data was collected through questionnaire from a sample of 45 respondents that were taken through census method and also interview was held with 10 families with clubfoot children. The data collected from the questionnaire was analyzed using statistical tools such as percentage and frequency statistical analysis. The major finding of the research showed that most of the families with children having club foot deformities face financial burden because of the demanding follow up treatment, which is every week for 6 to 8 weeks. In addition, working parents are challenged to take time off work every week for their children's treatment. However, families are hopeful that club foot is curable, and sustain the challenges of the treatment process. Families, on the other hand, have good relationships within their families, neighbors, and the community, and partially have a smooth social life. Based on the findings of the study, the researcher forwards sound recommendations. The study implies that there is a need to create public awareness regarding club foot deformity. The state should provide laws and policies that are disability oriented as well as educate the community regarding the types of disabilities in order to support the most vulnerable families. These preliminary findings contribute to knowledge concerning the life of Ethiopian families with disabled children. Moreover, the finding may help as an input to the Ethiopian authorities with regards to the needs of families taking care of disabled children.*

**Key words:** *Ethiopia, Disability, Family, Children, Club foot, Treatment*

## **CHAPTER ONE**

### **INTRODUCTION**

This chapter contains the introductory part of the entire study. It provides some insights about the ground and assumptions where the study is conducted. It states the background of the study, background of the organization, statement of the problem, research questions, objectives of the study, and target population.

#### **1.1. Background of the Study**

Disability is a universal phenomenon. It exists everywhere in the world. There are different kinds of different deformities. ILO (1985) describes that disability has different effects on different persons in that some may be temporary or permanent, partial or total, fixed or changeable, have profound or no apparent effect on the working life of a person. They can be classified on the basis of their causes, nature or other factors. Based on the cause or origin of the disability, it can be classified as: congenital or early childhood disability; war disability; industrial disability or occupational disease; accident in street, at home, at play; illness and disease (ILO, 1985).

Terusew, in his study done in 1993, classified disability on the basis its nature, disability as: orthopedic cases; blind; deaf; those with speech defects; those suffering from nervous disorders; the tuberculosis; paralyzed; and, the mentally retarded. Listed seven types of disability groups based on the “international classification of diseases and injuries”: the visual the blind and the weak sighted, the oral [the deaf and hard of hearing], the intellectual [mild, moderate and profound retardation], the motor [neurological, musculo-skeletal and crippling, chronic health conditions], the lingual [oral and/or graphic], behavioral [emotional and social] and the multiple disabilities (Terusew, 1993).

Raising a child with disabilities can affect family life in many ways both positively and negatively. Research has shown that levels of parenting stress might be increased compared to families having children with typical development. Regarding the disability, there is always an impact in all life domains of the family (Dardas & Ahmad, 2014).

A study done by Dardas and Ahmad (2014) stated that parents of children with autistic syndrome face challenges in their social life and at their work places. The families with autistic children tend to withdraw from activities that include social contact. Moreover, some parents seem to choose to quit their jobs in order to support their child together with the family members and professionals.

In a study concerning the impact of having a sibling with an intellectual disability, the majority of parents also reported benefits to their other children such as: tolerance and acceptance of differences, caring and compassion, maturity, patience, assistance/support, appreciation of own life and health. The study proved that there are some factors that have impact on the family life such as: personality of the child, type of disability, family style, mental health, attitude and parental well being (Mulroy, Robertson, et al. 2008).

When the condition is present from birth, the child's life and identity are shaped around the disability. In some ways, it may be easier for a child and his or her family to adjust to never having certain functional abilities than to a sudden loss of abilities later. Kingau (2018) mentioned in her studies that in Africa, the structural deformities are associated with stigma, which has a psychological and social effect on children, parents and caregivers. It is therefore important to understand the experiences of parents/ caregivers of children with clubfoot.

Almaz (2011), on her study on the attitudes of Ethiopian college students toward people with visible disabilities, found that the college students have negative attitudes toward

individuals with visible disabilities. On all three subscales of affect, behavior, and cognition, students' scores indicated that they held negative attitudes. Other studies indicate that children with disabilities experience stigma from birth and are prone to exclusion, cover up, leaving behind, institutionalization, and abuse. Families have hidden away children with disabilities, keeping them out of school and exclude from any opportunity to having a role in their family (Wegayehu, 2004).

We know that children face challenges in their everyday life, and the family have difficulties caring for their disabled children. But, what does the family life of the disabled children look like? This study aims to answer this question. It focuses on one of the health care institutions where physically disabled children get treatment; the study particularly focuses on the assessment of the family life of children with clubfoot disabilities. Regarding the family life of disabled children, conducted researches are insufficient specifically on the assessment of physically disabled children's family life in Ethiopia.

The study was taken place in Black lion hospital where there is a clubfoot clinic. Prior to 1972, the School of medicine was located on the main campus for preclinical training and the then Princess Tsehay Memorial Hospital (now, the Armed Forces General Hospital) for clinical training. Later, with the opening of the Tikur Anbessa Specialized Hospital (Black Lion hospital) in 1972, the hospital became the only site (at the time) for training Medical Doctors.

In 1998, Tikur Anbessa Specialized Hospital, the largest referral hospital in the country, with 700 beds, was transferred to the School by the Federal Ministry of Health, and it has since become a University teaching hospital. The Tikur Anbessa Specialized Hospital is now the main teaching hospital for both clinical and preclinical training of most

disciplines. It is also an institution where specialized clinical services that are not available in other public or private institutions are rendered to the whole nation.

There are various departments, faculties and residents under specialty training in the School of Medicine provide patient care in the hospital. Almost all regional and federal hospitals in Addis Ababa are affiliated to the School of Medicine as clinical services and training sites.

<http://www.aau.edu.et/chs/tikur-anbessa-specialized-hospital/background-of-tikur-anbessa-hospital/>

## **1.2.Statement of the Problem**

A number of researchers have worked on the different types of disabilities in Ethiopia. For example, research conducted on the nature and the difference of prejudice and discrimination against people with different types of disabilities (Tizita, 2014), a study done to examine the socio-economic challenges of women with disability in Hager Tibebe Maderaja Derijit, Addis Ababa (Eleni, 2016), Assessment of disabled children attitudinal & behavioral changes at Menagesha Rehabilitation Center of Cheshire services- Ethiopia in West Shoa Zone (Tekle Mariam, 2013), Experiences of persons with sensory disability and their vulnerability to HIV & AIDS (Etabezahu, 2013), The psychological, economical and social effects of Leprosy on affected women in A.A city administration (Rahel, 2016).

In general, it can be concluded that even though there have been studies done on the family life of children with physical disability in developed and some developing nations, as per the knowledge of the researcher, there appear to be insufficient studies that focus on the family life of children with physical disabilities in Ethiopia, particularly club foot

children in Black lion hospital. Therefore, I initiated this study to get more information to assess the family life of club foot children in Black Lion hospital.

### **1.3.Objectives of the Study**

This study has general and specific objectives.

#### **1.3.1. General Objective of the study**

The general objective of this study is to assess the family life of physically disabled children with a special reference to club foot children at Black Lion hospital in Addis Ababa.

#### **1.3.2. Specific Objectives of the Study**

The specific objectives of this study were:

- To identify if the disability of a family member affects the integrity of the family in Black Lion Hospital,
- To find out the challenges that the families face from having a child with clubfoot disabilities in Black Lion Hospital,
- To generate feasible suggestions and recommendations to concerned entities imitative to overcome the challenges.

### **1.4.Research Questions of the Study**

As the focus of this study is already mentioned above, the study tries to answer the following basic research questions.

- In what way does the disability of children affect the integrity of their families in Black Lion Hospital?
- What are the challenges that the families face from having a child with clubfoot disability in Black Lion Hospital?
- What are such challenges on the lives of families in Black Lion Hospital?

- What are the possible suggestions and recommendations that are required reduce the challenges in the area?

## **1.5. Scope and limitation of the Study**

### **1.5.1. Scope of the Study**

In terms of content/subjective scope, the family life of physically disabled children is taken as a comprehensive model, and specifically clubfoot disability was investigated. Other types of physical disabilities have been excluded from this study.

Under this study, considering all hospitals working on club foot treatment was difficult and unmanageable from the researcher's stand point. The reason why Black Lion hospital was chosen is because of its proximity to the researcher. Therefore, this study only focused on the parents/caregivers who bring their club foot children to Black Lion hospital for club foot treatment. Methodologically, this research focused on descriptive research design.

### **1.5.2. Limitation of the Study**

This study was confined to the club foot clinic at Black Lion hospital setting. The findings may not be representative of all parents following up treatment for their children in other hospital settings in other regions. Thus, the study results may not be generalized except to similar settings.

The findings of this study are based on a census sample of parents who brought their children for treatment at the clubfoot clinic. Thus, they might not be representative of other parents who have children with clubfoot undergoing similar treatment in other settings.

## **1.6. Significance of the Study**

The study theoretical and practical significance stated as follows:

### **1.6.1. Theoretical significance**

- The study is hoped to contribute to knowledge regarding the family life of children with club foot disability in Black Lion hospital through the voices of the parents/caregivers, which has not been given much attention in the scientific research.

### **1.6.2. Practical significance**

- Raise awareness regarding the challenges that the families face, to the public and the policy makers,
- Provide knowledge to the Ethiopian authorities regarding the needs of the families.

## **1.7. Operational Definitions of Terms**

### **➤ Physical Disability**

It is a limitation on a person's physical functioning, mobility, dexterity or stamina. Other physical disabilities include impairments which limit other facets of daily living, such as respiratory disorders, blindness, epilepsy and sleep disorders.

### **➤ Family life**

It is defined as the routine interactions and activities that a family has together. When members of a family enjoy each other's company and spend a lot of time doing things together, this is an example of a good family life.

## **1.8. Organization of the Study**

The study is divided into five chapters. Chapter one is divided into sub-sections, sets the background information to the research problem, statement of the problem, objectives of the study, research questions, scope and limitation of the study, significance of the study, operational definitions of terms, and organization of the study.



Chapter two assesses related review of literature. The literature review includes definition of disability and understanding what disability is, the situations of people with disabilities, service provision to children with disabilities in Ethiopia, the prevalence of disability in Ethiopia, the disadvantages of PWD, disability related stigma and discrimination, traditional beliefs and cultural values towards PWD, the difficulties that people with disabilities encounter, review of policies and strategies on people with disabilities in Ethiopia, and empirical studies.

Chapter three discusses the research design and methodology that consisted of description of the study area, research design, and universe of the study, sampling and sampling methods, tools for data collection, data analysis and interpretation, and ethical consideration.

Chapter four focuses on data analysis and interpretation: It presents data analysis, major findings, and interpretation of the study. Finally, chapter five deals with conclusions and recommendations of the study. The conclusions and recommendations are given based on the findings of study.

## **CHAPTER TWO**

### **REVIEW OF RELATED LITERATURE**

This chapter consists of reviewed literatures about understanding and defining disability, service provision to children with disabilities in Ethiopia, disability and family caregivers, types and classifications of disabilities, the prevalence of disability, the situation of persons with disabilities in Ethiopia, and review of national policies and strategies on people with disabilities in Ethiopia.

#### **2.1. Defining and understanding Disability**

WHO (2011) describes disability as “the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).

Disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning. Most extended families have a disabled member, and many non-disabled people take responsibility for supporting and caring for their relatives and friends with disabilities. Disability is a complex, dynamic, multidimensional, and contested (WHO, 2011).

The causes for disability are numerous but the major causes of disability in Ethiopia are man-made disaster (conflict, road accident, work related accidents, etc), prenatal causes, during natal and postnatal periods, alcohol and drug addiction, communicable diseases, harmful traditional practices, and they are aggravated by poverty related factors such as malnutrition, and lack of environmental hygiene (ADPD, 2010).

The relationship between health conditions and disabilities is complicated. Whether a health condition, interacting with contextual factors, will result in disability is determined by inter-related factors. Often the interaction of several conditions rather than a single one contributes to the relationship between health conditions and disability. Co-morbidity, associated with more severe disability than single conditions, has implications for disability. Also the presence of multiple health problems can make the management of health care and rehabilitation services more difficult. Chronic health problems often occur together. For example, one chronic physical health condition, such as arthritis, significantly increases the likelihood of another physical health condition and mental health conditions. So the aspect of disability that may be reported as primarily associated with one health condition may often be related to several coexisting conditions (WHO, 2011).

According to the World Health Organization (WHO), there are 300 million people with disabilities in the world out of which 210 million (70 percent) live in developing countries. Apart from demographic reasons, the high prevalence of disability in poor countries shows the existence of causal relationship between poverty and disability (ADPD, 2010).

Regarding the prevalence of people with disabilities in Ethiopia, African Decade of Persons with Disabilities (2010) stated that people with disability are slightly over 800 thousand in number constituting 1.1 percent of the population in Ethiopia in 2007 (showing reduction from 1.9 percent in 1994). In other words the new census implies that the PWD have depopulated by over 100 thousand in the 13 years interval. These percentages, in light of WHO's 10 percent threshold and the fact that Ethiopia is a typical developing country, makes the census result curiously dubious. The number reported by both censuses is far less than other estimates. Understandably, part of the reason for the

underestimation is the presence of strong cultural barriers to declare oneself or one's own child as disabled (ADPD, 2010).

Persons with one eye or one ear as long as the person is able to fully perform activities in the manner or within the range considered normal for a human being, even if his/her other eye or ear is blind or defective, he/she is not considered as disabled person. Unlike in the 1994 Census, Leprosy, Epilepsy, and Mental problem (except mental retardation) were not considered as disability. However, they could be causes of disabilities.

## **2.2. Understanding clubfoot deformity**

According Global foot initiative (2017), around 174,000 children – 1 in every 800 - are born with clubfoot globally every year. Clubfoot is a congenital deformity in which one or both feet are turned in and downward; if club foot is untreated it leads to life-long disability. Children born in high-income countries receive immediate corrective treatment and the vast majority lives a life unaffected by having been born with clubfoot.

The initiative further states that most children born with clubfoot in Lower and Middle-Income Countries (LMICs) face a different future. For those born today, less than 15% will access treatment. The rest will face a lifetime severely affected by their clubfoot – experiencing ongoing pain, limited mobility, and reduced opportunities in education, employment and relationships. The chair person of GFI made a statement that by 2030 they want at least 70% of children born with clubfoot in LMICs to access the treatment they need to walk and run free for the rest of their lives (GFI, 2017).

For people living with uncorrected clubfoot walking can be painful and extremely difficult. People living with disability in lower income countries are at higher risk of discrimination, physical and sexual abuse, neglect, illiteracy and inequality in almost all

aspects of society. Disability due to clubfoot also presents an economic burden on families and societies due to lost opportunities in education and employment (GFI, 2017).

### **2.3.The Situation of People with Disabilities**

According to the base line study done by ADPD, there is a high prevalence of disability in poor countries, and this shows the existence of causal relationship between poverty and disability. Disability is caused and aggravated by poor living condition, such as poor nutrition, lack of health and sanitation facilities and exposure to various forms of accident. On the other hand, in poor countries, disability makes it difficult for people to get out of poverty. The absence of rehabilitation centers, lack of (equal) access to education, employment and other services makes it particularly a struggle for PWDs to overcome livelihood challenges (ADPD, 2010).

The most affected groups among the disabled are those that are in developing countries in general, and women and children in particular. Statistics by international research organizations show that 80 percent of disabled persons in the developing countries (out of which more than 70 percent are women) do not have working opportunities. The same statistics shows that nearly 98 percent of children with disabilities are not in school while the same percentages of people with disabilities in developing countries do not have access to rehabilitative and other basic health services (ADPD, 2010).

SIDA, 2014 mentioned that only 3% of Ethiopia's estimated 2.4 to 4.8 children with disabilities go to school, due to stigma among parents and educators, inaccessibility, rigid teaching practices, poorly trained teachers and the lack of adapted learning resources. A survey conducted by the African Child policy forum in 2011 found that only 29% of children with disabilities were registered at birth (SIDA, 2014).

On the other hand, the 1994 census revealed that 85 percent of PWD live in rural areas, where there could be no enabling environmental factors for them to contribute to the labor force. Majority of those few who migrate to urban area make their living as beggars or on the merit of some charity organizations (ADPD, 2010).

According to SIDA, the civil society is playing a major role in the financing and delivering of services for people with disabilities within all areas of welfare. SIDA mentioned a survey done by ACPF revealed that specialized health care services for children with disabilities in Ethiopia, and in particular rehabilitation, were predominantly offered by NGOs (SIDA, 2014).

The study by ADPD also stated that there is still some doubt on the functionality of the legal and policy environment in setting the stage for giving full recognition to PWD. There is a sense that the issues of disability are sidelined from major international development goals such as the MDG. Given the proportion of disabled people and the situation in which they live, it is difficult to imagine meeting the MDG goals without improving the lives of PWD (ADPD, 2010).

#### **2.4. Service provision to children with disabilities in Ethiopia**

Many people with disabilities do not have equal access to health care, education, and employment opportunities, do not receive the disability-related services that they require, and experience exclusion from everyday life activities. Following the entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), disability is increasingly understood as a human rights issue. Disability is also an important development issue with an increasing body of evidence showing that persons with disabilities experience worse socioeconomic outcomes and poverty than persons without disabilities (WHO, 2011).

Understanding the lack of adequate services to disabled children in Ethiopia, Cure hospital started operation in Addis Ababa in 2008 to provide modern medical and surgical care to physically disabled children. As Ethiopia consistently ranks among the poorest countries in the world, with few of its citizens having access to medical care, there is a great need for this level of care. Cure hospital provides a superior care for the children of Ethiopia through a combination of in-hospital care, mobile clinics, and club foot clinics. (<https://cure.org/ethiopia>).

Children with different types of disabilities travel from all regions of Ethiopia go to Cure hospital to get service. Cure currently works with CBM to enhance club foot program. Cure Hospital has 32 service points (clinics) set in different regions of Ethiopia to deliver the service, of which two club foot clinics are in Addis Ababa- Cure hospital and Black Lion hospital.

Makeda, in her article written in 2017, stated that the Catholic Church in Ethiopia has been dealing with the problem of deformities and other disabilities from all over the country which affects not only the body but also the social and psychology of the children. Alemachin, since its establishment in 1972, has been working with different health institutions to provide medical treatment for the children. With its fully equipped physiotherapy rooms and playgrounds, learning and recreational sessions, healthy and nutritional diets, very clean environment and dedicated staff make sure the children go back to their families fully healed not just physically but also psychologically and with good manners.

## **2.5.The Prevalence of Disability in Ethiopia**

For poor countries like Ethiopia the only source of data to understand the prevalence is the national census whereas in developed countries they conduct surveys specifically designed for gauging disability prevalence rates. The problem of under reporting

disability (disability in hiding) is particularly common in developing countries where awareness levels are generally low. Good illustration for this is the contrast in the prevalence rate of disability in countries such as Kenya, Ethiopia, India and Bangladesh (reported as below 3 percent) whereas countries like New Zealand, USA and Canada report above 15 percent (ADPD, 2010).

According to Tirussew's study on disability (2005), the social relations are manifested in marginalized interpersonal relationships and participation at family, neighborhood and the community levels. PWDs have limited provision of public services and special programs, such as health, education, transportation, information, recreational activities and legal provisions. They also have restricted involvement in socio- cultural, sports and recreational activities as well as discriminatory practices in employment opportunities. Above all the quality of interpersonal relationships and scope of participation in socio-cultural activities which entail a degree of acceptance, love, care and respect, as well as the range of involvement in mainstream socio-economic activities are very critical for personal development.

Many of PWDs developed depression, frustration, irritability and feeling of helplessness and self-hatred. Deaf children suffer from lack of communication with their peers and teachers in regular ordinary schools. Teachers do not understand deaf children; rather they ridicule, irritate and made them hopeless. During the class session, deaf students try to gaze at teachers to read the movements of their lips (Tirussew, 2005).

ADPD presented the census figures that were conducted in 2007 and other studies. The data revealed that people with disability are slightly over 800 thousand in number constituting 1.1 percent of the population in Ethiopia in 2007 (showing reduction from 1.9 percent in 1994). Nearly a third of PWD are over 50 years old in Ethiopia implying causal relationship between old age and disability. Other studies conducted in 1995 at



regional level estimate that PWD constitute 12.7, 14.0 and 16.8 percents of Oromia, Amhara and SNNP regions respectively (the three most populous regions in Ethiopia by order of their population size). In 2006, the national prevalence of blindness and low vision were 1.6 and 3.7 percents respectively. Significant variability in the prevalence of blindness is observed across regions, ranging from the highest 5.4 percent in Somali region to the lowest 0.7 percent in SNNP region. Less than one percent children with disability have access to rehabilitation service, and less than 2 percent of disabled children in school age have access to education that has special need facility (ADPD, 2010).

### **2.5.1. Disadvantages of People with Disability**

According to the Ministry of Labor and Social Affairs, 95% of persons with disabilities in the country live in poverty - the vast of majority in rural areas, where basic services are limited and the chances of accessing rehabilitative or support services are remote. According to Handicap International, only 3% of Ethiopia's estimated 2.4 to 4.8 million children with disabilities go to school (SIDA, 2014).

Despite some encouraging effort in recent years, there is little noticeable adjustment in the school system that would help to accommodate the need of disabled people. Lack of access to employment is the major challenge for disabled people. According to official information from the 1994 census, 85 percent of PWD live in rural areas, where there could be no enabling environmental factors for them to contribute to the labor force. Majority of those few who migrate to urban area make their living as beggars or on the merit of some charity organizations (ADPD, 2010).

Also while disability correlates with disadvantage, not all people with disabilities are equally disadvantaged. Women with disabilities experience the combined disadvantages

associated with gender as well as disability, and may be less likely to marry than non-disabled women. People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments. People with more severe impairments often experience greater disadvantage, as shown by evidence ranging from rural Guatemala to employment data from Europe. Conversely, wealth and status can help overcome activity limitations and participation restrictions (WHO, 2011).

### **2.5.2. Disability-Related Stigma and Discrimination**

Negative attitudes towards disability can result in negative treatment of people with disabilities, for example: children bullying other children with disabilities in schools, bus drivers failing to support access needs of passengers with disabilities, employers discriminating against people with disabilities, and strangers mocking people with disabilities. Negative attitudes and behaviors have an adverse effect on children and adults with disabilities, leading to negative consequences such as low self-esteem and reduced participation. People who feel harassed because of their disability sometimes avoid going to places, changing their routines, or even moving from their homes (WHO, 2011).

Adults with disabilities face difficulties although they are not developed mentally, and are vulnerable like children with disabilities. The range of their participation in community affairs such as local community organizations, festivals, weddings, funerals and other social occasions are highly limited. PWDs, particularly the ones with severe physical and mental disabilities suffer from stigma and discrimination. Other studies confirm that some impairment create a great disadvantages of social stigma for individuals, while other does not (Patricia et al., 1999).

Having a disability can create difficulties in one's daily activities. In most surveys, the respondents were asked to describe levels of difficulty in performing some basic daily activities, including: eating and/or drinking, hearing and/or speaking, seeing, moving/walking, communication, and personal hygiene. Levels of difficulty in the analysis include: no difficulty (a person can do it by himself/herself without the need of someone's support or the use of instrumental aids), some difficulty (self-performance with some difficulties but without someone's support or the use of aids), and substantial difficulty and cannot perform without support or the use of aids (Setotaw, 2007).

Based on the 1994 survey and information obtained from Ministry of education the percentage of children in special need education program was nearly negligible. Despite some encouraging effort in recent years, there is little noticeable adjustment in the school system that would help to accommodate the need of disabled people. Lack of access to employment is the major challenge for disabled people. According to official information from the 1994 census, 85 percent of PWD live in rural areas, where there could be no enabling environmental factors for them to contribute to the labor force. Majority of those few who migrate to urban area make their living as beggars or on the merit of some charity organizations (WHO, 2017).

## **2.6. Review of National Policies and Strategies on People with Disabilities in Ethiopia**

Following the provision on the 1995 Ethiopian constitution, various sectoral policies are crafted. Particularly Social welfare, Education, Health and Sport policies were developed in mid 1990's have clearly outlined policy directions in favor of PWD. Sectoral policies were made to be part of the triple five-year plans of what has become famously known as Plan for Accelerated Sustainable Development to End Poverty (ADPD, 2010).

### **2.6.1. The Social Welfare Policy**

This policy distinguishes the issue of persons with disability at parallel level with other society segments such as youth, women and the elderly whose social welfare is usually a priority of concern. The highlights of the policy mentions major problems, among others – the fact that most PWD live in rural areas and that have limited to no access to social and medical facilities, they are relatively highly exposed to harmful traditions and social stigma, they have limited opportunity for education and employment, their potential to attend normal life activities is constrained by absence of friendly physical environment. Coupled with the stigma and fatalistic view of the society their likely destiny is life-long dependence on other people such as begging.

The policy draft has also stipulated policy actions that have to be implemented in addressing these concern areas directly related to PWD. The pointes are stated as follows:

- Conditions that will enable persons with disabilities to use their abilities as individuals or in association with others to contribute to the development of society as well as to be self supporting by participating in the political economic and social activities of the country shall be facilitated.
- Efforts aimed at instilling in person with disabilities a sense of confidence and self-reliance through education, skill training, gainful employment opportunities and other services shall be increased and appropriate legislative measure shall be taken to ensure their welfare.
- Mechanisms shall be created by which persons with physical and mental impairment will receive appropriate medical/health services and supportive appliances.
- Mechanisms by which PWD can receive appropriate support service in the context of their family and community environment shall be created.
- All effort shall be made to establish special centers where PWDs without any family will be cared for.

- Appropriate and sustainable educational program shall be launched to significantly raise the level of public awareness concerning the determinants of and consequence of the problems of PWD as well as to change the prevailing harmful traditional attitudes, norms and practices in respect to PWDs.
- Strategies and programs designed to increase our understanding of the causes and prevalence of physical and mental disability and thereby prevent and mitigate their spread shall be formulated.
- All effort shall be made to gradually remove all physical impediments and make residential areas, work and other public places more physically accessible to PWDs.
- Support and assistance shall be provided to community action-groups, NGOs, voluntary association involved in providing service to PWDs (ADPD, 2010).

Based on this policy a national development plan in which many line ministries participate is formulated. MOLSA was being placed at the centre shoulders the responsibility to coordinate the implementation by involving the line ministries. The highlights of the policies concerning PWD will be mentioned below:

### **2.6.2. Education and Training Policy (TGE 1994)**

The education and training policy (TPE) had a sub-objective aimed at achieving educational equity to all groups including persons with disabilities. Also in reference of the proposed reform of educational structure it states: “Special education and training will be provided for people with special needs”.

MoE launched “strategy for special needs Education program” (MoE, 2006). The core elements of the strategy were on promoting inclusive education system and inclusive schools with an aim to meet the goals of UPEC and EFA15. It outline a range of actions for improving access to education and underlines on the need to give affirmative actions

to those deemed as disadvantaged society groups such as females, pastoral and semi-pastoral resident individuals and those with special needs (ADPD, 2010).

### **2.6.3. Health Policy**

The Ethiopian health sector policy that is currently in use has been developed in 1993. The policy has defined the priority groups for whom the health service facilities have to be improved. Among these are women, children and people in remote (rural areas). The policy has also deliberated that the approach of health service has to mainly follow preventive approach such as the use of Information, Education and Communication (IEC), environmental health, Occupational health and safety. With regard to curative service priority is given to provision of new health facilities in areas where the service has not reached, rehabilitation of existing health facilities, curative and rehabilitative health facilities such as for mental health problems, control of communicable disease, etc. (ADPD, 2010).

With regard to specific policy and strategic provision for PWD, however, the health sector (ministry of health) is relatively ineffectual. The policy has not mentioned the case of PWD in a direct way or as distinct priority groups. The sectoral strategy has not exclusively treated or even mentioned PWD, as group that need particular consideration (ADPD, 2010).

### **2.6.4. HIV/AIDS Policy**

HIV/AIDS is recognized as social problem whose prevention and control actions have to be envisaged not only in the health sector but also in all sectors of the country. With this in mind a comprehensive HIV/AIDS policy has been developed in 1998 and followed by subsequent strategy for mainstreaming the policy into development strategies of all sectors/ministries.

The policy has been effective in helping various society groups to benefit from projects however the policy, just like the national health policy, has failed to acknowledge the PWD as a distinct group that needs separate strategy and actions. As a result of this omission, PWD (particularly women), remained vulnerable to the pandemic and missed the opportunity to benefit from the policy/strategic attention they deserved (ADPD, 2010).

#### **2.6.5. Sport Policy of the FDRE (Ministry of Youth and sport April 1998)**

Similar to the other multi-year sector development plans, the ministry of youth and sport has developed policies that in many ways touch the lives of PWD. The sport segment of the ministry has outlined major policy objectives and methods for implementing them in the broader sectoral strategy. In line with its policy in educational institutions, health & fitness institutions, it gives considerable attention to PWDs (ADPD, 2010).

The policy document issued by the ministry in 1998 has stated the following two objectives as part of the broader sectoral objective in the multi-year development strategy: to give special attention to disabled students and facilitate their participation in sports suitable for their physical conditions; to ensure the participation of PWD in sports activities at their locality, educational institutions and working places and to also ascertain their equal sharing of the benefits (ADPD, 2010).

#### **2.7. Empirical studies**

Quality of life of individuals is closely related to the Quality of life of those around them, including partners or parents. Therefore, any chronic illness carries the potential to impact on the life of the family. Compared to parents of healthy children, parents of children with chronic disease report lower self- development, restrictions on their well being and emotional stability and lower levels of daily functioning (Golics et al.).

Most studies on quality of life focus on assessing the quality of life of patients. Family quality of life has been explored in dermatology, oncology, and in the field of physical and mental disability, but little is known about the impact of disease on families of patients in many other specialties. For example, it is found that 38% of adolescents with dermatological conditions felt that their family relationships had been affected as a result of their conditions (Golics et al).

The Minnesota Governor's Council on quality assessment in 2000, to determine how people with developmental disabilities evaluate the quality of services they receive from different service providers. For instance, the study revealed that 24% of parents/advocates are not satisfied with the education provided to people who have developmental disabilities (MRI, 2001).

Regarding the challenges people with developmental disabilities have, it is found that being economically self-sufficient (79%), living independently (74%), and learning (73%) are the most significant challenges for them. On the other hand, people feel included in activities with family and friends (95%), but not within society as a whole in terms of being treated as an equal (51%) agreement (MRI, 2001).

In a study conducted in the United Kingdom (Dobson B et al., 2001), parents of a disabled child spent on average twice as much on comparable categories of expenditure as parents whose child did not have a disability (£65.51 and £31.22 respectively), despite the fact that parents of disabled children have incomes well below the national average.

From the study reports that we have seen above, the life of families caring for a disabled child is affected in different aspects, one of the major things being financial burden.



## **CHAPTER THREE**

### **RESEARCH DESIGN AND METHODS**

This study aims to meet three research objectives: To identify if the disability of a family member affects the integrity of the family in Black Lion Hospital, to find out the challenges that the families face from having a child with clubfoot disabilities in Black Lion Hospital, and to generate feasible suggestions and recommendations to concerned entities imitative to overcome the challenges.

To address these objectives, this study has adopted the appropriate research methods and approach. Following the internalizing of the problem to be studied and the assessment of physical disabled children's family life that backs chapter one and chapter two, this chapter presents the methodology of the study. The methodology part attempts to describe the methods through which the objectives of the study could be met. It states about the research design, population and sampling procedures, data gathering methods and data collection methods, validity and reliability of the study, methods of data presentation and analysis, and ethical considerations.

#### **3.1. Research Design**

Research design is the conceptual structure within which research is conducted. Chopra (2012) indicated that "a research design is the arrangement of condition for collecting and analysis of data in a manner that aims to combine its relevance to the research purpose with economy in procedure". A research design is the arrangement for a precise statement of goals and justification.

According to Zegeye (2009), the goal of descriptive research is to describe some aspect of a phenomenon, i.e., the status of a given phenomenon. Hence, among the different

types of research designs the researcher will use descriptive research design. The rationale for using descriptive research design is because it helps to describe the nature of existing conditions, or identify standards against which existing conditions can be compared, or determine the relationships that exist between specific events.

The other qualitative approach describes the actual condition of physically disabled children's family life in non-numerical ways. So, to show the physically disabled children's family life, the explanatory type of study was used because of the desire to know "why", and explain the reason.

The main objective of this study is to assess physically disabled children's family life in Black Lion hospital. In order to achieve the stated objectives, quantitative and qualitative research approaches are used. The aim of the quantitative approach is to assess physically disabled children's family life in the study area through utilizing quantitative data to estimate statistically specific measurements that can be representative of the target population, parents/caregivers that come to clubfoot clinic in Black Lion hospital for the treatment of their club foot children.

### **3.2.Universe of the Study**

According to Zikmund et al. (2010) and Kothari (2004), a population refers to all items in any field of inquiry and is also known as the 'universe'. The study involves the families/caregivers of children coming to the clubfoot service point at Black Lion Hospital. The study was employed at Black Lion Hospital. The actual population of the respondents is fifty (50 respondents). Hence, the sample unit for this study considered the total numbers of respondents at Black Lion Hospital currently encompass exactly 50 respondents, i.e. (N= 50). Considering this reality, the researcher took all the population that was present in different clinic days by using census method.

### **3.3.Sampling and Sampling Methods**

According to Kothari (2004), non-probability sampling is that sampling procedure which does not afford any basis for estimating the probability that each item in the population has of being included in the sample. In this type of sampling, items for the sample are selected deliberately by the researcher; his choice concerning the items remains supreme. Therefore, this study used purposive/judgmental sampling method.

### **3.4.Tools for Data Collection**

There are two sources of data; these are primary and secondary sources. The researcher used both primary and secondary sources to collect data. Primary data is the information that the researcher finds out by him/herself regarding a specific topic. The main advantage with this type of data collection is that it is collected with the research's purpose in mind so it's more consistent with the research questions and purpose.

A well-designed questionnaire was used as the best instrument to collect primary data. Close ended questionnaires which are designed on an ordinal scale of measurement basis was used to collect primary data, so that the variables could be ranked to measure the rating of the respondents with the variables. Few open ended questions were also included in the questionnaire. The source of primary data for this study is parents/caregivers of children with club foot deformity that come to the club foot clinic in Black Lion hospital. The questionnaires were completed by the parents/caregivers of children with club foot deformity at Black Lion hospital.

The appearance and layout of the questionnaire was constructed in a way that encourages participation of the respondents to complete the questionnaire. The wording and phrasing of the questions were kept as concise as possible, and the questions were measured using Rating scale.

In addition, an Interview schedule was employed to collect views from the respondents concerning the assessment of physically disabled children family life. The researcher prepared in-depth interview questions for parents/caregivers, since interviews have power to measure the respondents' opinion, attitudes, and beliefs.

Secondary data are those which have already been collected by someone other than the investigator himself. The source of secondary data are library books, international journals, research papers, research papers related to the topic, internet, etc. This data were used to get better insight on the research topic, and to design the sample frame and questionnaire for retrieving the primary data. Another advantage of using secondary data is to validate and compare the data collected through questionnaire to existing literature and articles.

After the selection of the site of the study, the Black Lion hospital was asked for permission to collect data. At the inception of data collection, the consent of participants was asked. Following this, the purpose of the study explained to the participants, and they were given orientation on how to respond to the questionnaire. The data were then collected by field surveyors using the questionnaire to each parent/caregiver and partly by the researcher.

### **3.5.Data Analysis and Interpretation**

A quantitative and qualitative method was used to analyze the data. The statistical characteristics of physically disabled children's family life- specifically children with clubfoot disabilities, was summarized using a descriptive statistics; frequency and percentage used for each of the physically disabled children's family life items.

To maintain the quality of data the researcher employed a pilot test is to check the reliability and adequacy of the questionnaires with selected target group of the study.

Then, the questionnaires were filled out in Black Lion hospital, and the collected data were analyzed using statistical package for social science (SPSS) version 16.0. Five items were discarded because of lack of complete information; therefore only 45 questionnaires were used for analysis.

### **3.6.Ethical Considerations of the Study**

Ethics is generally considered as dealing with beliefs about what is right or wrong, proper or improper, and good or bad. The following measures were taken while planning and conducting the study to ensure that the right and welfare of each subject is protected, and that nobody was harmed in any way during the research procedures.

The researcher has received informed consent from every respondent before having the questionnaires filled out. The researcher informed the respondents about the goals of the study and what the researcher hoped to achieve. The researcher was open and honest with the respondents, and respondents were not misled during the study.

Information obtained from respondents remained confidential. The collected data was anonymous; the researcher has not linked names or identified the finding about the respondents. In addition, the researcher ensured that the respondents in the study did not experience any discomfort in responding to the questions asked. Finally, the researcher was cautious during the dissemination of findings to ensure accuracy of the study, and adhered to the ethical consideration of the study.

## **CHAPTER FOUR**

### **DATA PRESENTATION, ANALYSIS AND DISCUSSION RESULTS**

This chapter attempts to present, analyze and interpret the data collected and relate them to the theory discussed in the second chapter of the paper. At the same time, the data is analyzed in association with the research questions raised in Chapter One. The center of focus of the presentation and analysis of data, this being the main objective of the study, are pieces of information that are only related directly to the assessment of physically disabled children's family life in the case of club foot children at Black Lion hospital.

In this chapter, results of the analysis was discussed and presented. Data collected through the survey were analyzed quantitatively using SPSS 16.0. The data, as has been discussed in the preceding chapter, were gathered from primary source through self-administered questionnaire and structured in-depth interviews with the researcher. In terms of organization, this chapter is put into two subparts. The first subpart deals with the descriptive analysis, and the second subpart discusses the interview analysis of the topic under study.

First, the quantitative analysis of the survey is presented. In order to present the analysis in an organized manner, the analysis was made in the order of the objectives of the research that are:

1. To identify if the disability of a family member affects the integrity of the family in Black Lion Hospital,
2. To find out the challenges that the families face from having a child with clubfoot disabilities in Black Lion Hospital,
3. To generate feasible suggestions and recommendations to concerned entities imitative to overcome the challenges.

#### 4.1. Response Rate

Table 4.1: Response Rate of Questionnaire

Number of Questionnaire Returned	Target Number of Respondents	Response Rate (%)
45	50	90

Source: Own survey, 2018

A total of fifty (50) questionnaires were distributed to the respondents and out of these questionnaires a total of 45 questionnaires were successfully completed and returned. The total response rate was 90 %. As a result, the analysis of this research is based on the number of questionnaires collected.

#### 4.2. Demographic Characteristics of Sample Respondents

Descriptive analysis is used to look at the data collected and to describe the data captured through the questionnaire. It was used to describe the demographic factors for more clarification. It is mainly important to make some general observations about the data gathered for general or demographic questions. This analysis is used to convert the raw data in a more descriptive way that provides us relevant frequencies and also the demographics like gender, age etc (Zikmund, 2012).

The researcher collected demographic information on the respondent's sex, marital status, residence (region), and whether it is urban/rural, age, employment status, education level, person who brought the child to the hospital, the child's age, how long has the child been following up for the treatment, and if the family attended to the treatment regularly. The findings are presented in Table 4.2.

Table 4.2: Demographic Characteristics

Description	Category	Frequency	Percent
Sex of respondents	Male	18	40.0
	Female	27	60.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Marital status of respondents	Married	43	95.5
	Divorced	2	4.4
	<b>Total</b>	<b>45</b>	<b>100</b>
Residence(region) of respondents	A.A	17	38.0
	A.A sp. Zone	13	29.0
	Oromia	3	6.0
	Other	12	27.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Urban/rural	Rural	13	29.0
	Urban	32	71.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Age of respondents	18-25	14	31.0
	26-35	28	63.0
	35-45	3	6.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Employment status	Employed	6	13.0
	Self-employed	19	42.0
	Unemployed	13	29.0
	House wife	7	16.0
	<b>Total</b>	<b>45</b>	<b>100</b>

Source: Own survey, 2018

With regards to the sex of the respondents, the study showed that 60% of the participants were female whereas the rest of 40% were male respondents. The survey analysis shows that, most of the respondents were female respondents. Regarding to the marital status the study showed that 96% of the participants were married and of 4% were divorced. The



survey analysis reflects that, most of the respondents were married. Concerning to the residence (region) of participants the study showed that 38% of the participants were Addis Ababa region residents, 29% of respondents were residents from Oromia special zone, 6% of participants were Oromia region residents, and 27% are from other areas. It can be said from the survey that, most of the participants were Addis Ababa region residents and those who live in Oromia special zone that are towns not very far from Addis Ababa.

With reference to whether they live in an urban/rural area, the study showed that 71% of the participants were urban area residents and 29% were rural area residents. It can be said from the survey that, most of the participants were residents from urban areas. The findings indicate that the age respondents fall under the range of 26-35 (63%), 18-25 (31%), and 35-45 (3%). It can be said from the survey that, most of the respondents were under the range of 26-35. Concerning the employment status of respondents, 42% of the respondents were self-employed, 29% of the respondents were unemployed, 16% of the respondents were housewives and, 13% of were employed. The survey analysis shows that, most of the respondents were self-employed.

Table 4.3 Respondents' educational status and related information

Description	Category	Frequency	Percent
Education level of respondents	Illiterate	4	9.0
	Read and write only	12	27.0
	Primary (1-8)	8	18.0
	Secondary (9-12)	13	28.0
	Higher education	8	18.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Person who brought the child to the hospital	Father	3	7.0
	Mother	23	51.0
	Mother and father	19	42.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Child's age	Less than 6 months	20	45.0
	6 months to 1 year	10	22.0
	1 year and above	15	33.0
	<b>Total</b>	<b>45</b>	<b>100</b>
How long has their child been following up for the treatment	1 - 6 month	23	51.0
	6 month - 1 year	14	31.0
	1 to 2 years	2	5.0
	Above 2 years	6	13.0
	<b>Total</b>	<b>45</b>	<b>100</b>
If they were attending to the treatment regularly	Yes	38	84.0
	No	7	16.0
	<b>Total</b>	<b>45</b>	<b>100</b>

Source: Own survey, 2018

The educational background of the respondents who accomplished education to a higher level represented 18% of the overall respondents ; secondary education (9-12) represented by 28%; primary school education (1-8) represented by 18%, those who can only read and write constitute 27% of the respondents, and finally 9% of the respondents

were illiterates. The table can be said from the survey that, most of the respondents have reached a level of secondary school. The lowest number of respondents was Illiterates.

Regarding the person who brought the child to the hospital, 51% of the respondents who brought the children to the hospital were the mothers, 42% of the respondents were mother and father together, and finally, 7% were father. From this analysis it is possible to conclude that most of the respondents who brought their children to the clubfoot clinic were the mothers. Concerning the age of the child, the data indicates that less than six months has scored 45%, six months to one year has scored 22%, and finally, 33% of the children were one year and above. From this we can understand that, most of the children are less than six months, and children who are six months to one year children are the lowest.

With regards to the duration of time that the respondents' children have been following up with the treatment, those who have followed up the treatment for 1- 6 months are 51%, 6 months to 1 year are 31%, 1 to 2 years are 5% and finally, above 2 years are 13%. This shows that the majority of the respondents of the respondents have followed up the treatment for are 1- 6 months. Regarding to attending to the treatment regularly, 84% of the respondents said "Yes"; and 16% of the respondents said "No". It can be said from the survey that most of the respondents are attending to treatment regularly.

#### **4.3. Descriptive Statistics**

Descriptive analysis is used to present the data collected in relation to the demographic factors. The summary of descriptive statistics that was intended to give general descriptions about the data is presented below. Accordingly, frequency and percentage values of each variable are used so as to show the overall trend of the data. Descriptive analysis is used to make a complete picture or profile of the basic component and angles

of the whole study. In the descriptive analysis, the unprocessed data collected in the form of a questionnaire was interpreted and analyzed.

#### 4.3.1. Difficulty of families in attending treatment

Table 4.4 Difficulty of families in attending treatment

Description	Response	Frequency	Percent
Is it very expensive to attend treatment?	Yes	38	84.0
	No	7	16.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Do you have the time to attend to treatment every week?	Yes	44	98.0
	No	1	2.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Do you have anyone to leave other children with at home?	Yes	24	53.0
	No	21	47.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Is your home very far from the hospital to make it every week?	Yes	36	80.0
	No	9	20.0
	<b>Total</b>	<b>45</b>	<b>100</b>
If the treatment process interferes with attending to work	Yes	36	80.0
	No	9	20.0
	<b>Total</b>	<b>45</b>	<b>100</b>
Any other problem in attending the treatment	None	36	80.0
	Financial Problem	7	15.0
	Transportation Problem	2	5.0
	<b>Total</b>	<b>45</b>	<b>100</b>

Source: Own survey, 2018

The above table 4.4 shows the response to the question asked if it is it very expensive to attend treatment shows that 84 percent of respondents from the club foot in Black Lion have said “Yes” and 16% percent said “No”. From this we can say that the majority (84 percent) of the respondents agreed that attending to the treatment is very expensive. It should be noted that the hospital renders the service for free, and the respondents are talking about their other expenses.

Respondents were asked if they have time to attend to treatment every week. The response received indicated that 98 percent of respondents have responded ‘Yes’, and this shows that parents have the time to come to the clinic every week for the treatment of their children. Two percent responded “No”, and this implies that it is difficult for them to make the time to follow up with the treatment every week.

The other question asked was whether or not they have to leave other children at home. For this, 53 percent of respondents said “Yes” and 47 percent of respondents have said “No”. From this, the researcher has realized that there are parents who have to leave other children at home when they come to the hospital for their children’s treatment for clubfoot.

Table 4.4 depicts that the majority (80 percent) of the respondents have responded “Yes” to the question asked if their home is very far from the hospital to make it every week for the treatment, 20 percent of the respondents have said “No”. This indicates that most of the families come for the treatment of their children from far areas.

The respondents were asked if the treatment process interferes with attending to work. 80 percent responded “Yes” to the question, and 20 percent responded “No”. Form this statement it is possible to conclude that for the majority of the respondents, coming for their children’s treatment on a regular basis has interfered with their woks.

Respondents were asked an open question to know if they have any other problem in attending club foot treatment. Their response indicated that 80 percent have said “None”, 15 percent have responded “financial problem”. For 5 percent of the respondents “transportation problem” was their answer.

This shows that the main problem in attending clubfoot treatment is the treatment process interfering with attending to work, and according to the above result, financial and transportation problem are noted to be problems to few of the respondents.

#### 4.3.2. Family Relationship

Table 4.5 Family relationship

Description	Response	Frequency	Percent
Relationship with spouse after child was born with clubfoot deformity	Weakened	3	7.0
	No Change	40	88.0
	Not Around	2	5.0
	Total	45	100
Rating level of support from close relatives in caring for a child with club foot	Poor	1	2.0
	Fair	9	20.0
	Good	13	29.0
	Very Good	20	45.0
	Not Around	2	4.0
	Total	45	100
Rating level of support from spouse in caring for a child with club foot	Poor	6	13.0
	Fair	17	38.0
	Good	3	7.0

	Very Good	19	42.0
Rating level of respondent's participation of family's day to day activities	Total	45	100
	Poor	5	11.0
	Fair	10	22.0
	Good	21	47.0
	Very Good	9	20.0
	Total	45	100
Rating the time given to family in the house	Poor	8	18.0
	Fair	12	27.0
	Good	22	49.0
	Very Good	3	6.0
	Total	45	100
Is having a clubfoot child been a challenge in your family?	Yes	25	60.0
	No	20	40.0
	Total	45	100
If yes, what is the challenge?	Shortage of Money	13	29.0
	Lack of time for self	32	71.0
	Total	45	100

Source: Own survey, 2018

As far as relationship with spouse after child was born with clubfoot deformity is concerned, 3 percent of the respondents responded that their relationship with their spouses has weakened, 88 percent of the respondents responded that there is no change

to the relationship, and 5 percent of the respondents that their spouses are not around. From this, we can conclude that for most respondents bearing a child with a clubfoot deformity does not have effect in their relationship with their spouses.

With respect to rating the level of support from close relatives in caring for a child with club foot, 2 percent of the respondents rated “poor”, 20 percent of the respondents “fair”, 29 percent of the respondents “good”, and 45 percent of the respondents rated “ very good” and 4 percent of the respondents said that they are not around. Based on the major responses of the respondents, we can conclude that the respondents get support from close relatives in caring for their children with club feet.

Respondents were asked to rate the level of support from their spouses in caring for a child with club foot. Of the respondents 13 percent rated “poor”, 38 percent of the respondents rated as “fair”, 7 percent of the respondents rated “good”, and 42 percent of the respondents rated “very good”. From this, the researcher can conclude that most couples support each other well in caring for their club foot children.

Concerning the level of the respondent's participation in family's day to day activities, 11 percent of the respondents rated that their participation was “poor”, 22 percent rated “fair”, 47 percent of the respondents are rated “good”, and 20 percent of the respondents rated their answers as “very good”. Hence, we can say that families with clubfoot children have good participation in their family's day to day activities.

As far as rating the level of time given to family in the house is concerned, 18 percent of the respondents rated the time they give to their family in the house as “poor”, 27 percent of the respondents rated as “fair”, 49 percent of the respondents rated as good, and 6 percent of the respondents rated as “very good”. Most families rated “good” and “fair” to the level of time they give to their families.



Respondents were asked if having a clubfoot child been a challenge in their families. The result indicated that the majority (50 percent) of the respondents has responded “Yes”, and 40 percent responded “No” to the question. Of those who answered “yes” the majority (71 percent) of the respondents mentioned shortage of money as being the challenge, for 29 percent of the respondents, lack of time for self was their challenge. For most respondents, caring for a disabled child and attending to the club foot treatment process must have added extra burden to their lives to have time for themselves.

### 4.3.3. Family’s Social Life

Table 4.6 Family’s Social Life

	Response	Frequency	Percent
How would you rate your relationship with people in your community?	Poor	3	7.0
	Fair	19	42.0
	Good	23	51.0
	Total	45	100
How would you rate your relationship with your neighbors?	Poor	5	11.0
	Fair	15	33.0
	Good	25	56.0
	Total	45	100
How would you rate your participation in the activities of your neighborhood	Poor	5	11.0
	Fair	15	33.0
	Good	23	51.0
	Very good	2	5.0
	Total	45	100

Things unable to do in the community because of a child with clubfoot	None	39	86.0
	Move around easily	2	4.4
	Not being available when I am needed	2	4.4
	Work well	2	4.4
	Total	45	100
If having a child with club foot has impact in relationship with the community	Yes	2	4.4
	No	43	95.6
	Total	45	100
If respondent ever felt of being secluded from the neighborhood because of having a club foot child	Yes	4	9.0
	No	41	91.0
	Total	45	100
If respondent ever felt ever faced discrimination in his/her community because of his/her club foot child	Yes	1	2.0
	No	44	98.0
	Total	45	100

Source: Own survey, 2018

As far as the relationship of respondents with people in their communities is concerned, 7 percent of the respondents rated their relationship with people in their communities as being “poor”, 42 percent of the respondents rated as “fair”, and 51 percent of the respondents as “good”. The researcher can conclude that majority of families with children having club foot deformities have good relationships (51%) with people in their communities, and others (42%) have fair relationships.

As to the respondent’s relationship with their neighbors, 11 percent rated their relationships as “poor”, 33 percent as “fair”, and 56 percent as “good”. Based on

the major response of the respondents the investigator can conclude the relationship of the respondents with neighbor as being “good”. Families having good relationship with their neighbors might help them to get assistance with their children when needed.

Respondents were asked to rate their level of participation in activities of their neighborhood. The response reveals that 11 percent of the respondents rated their level of participation in their neighborhood activities as “poor”, 33 percent of the respondents rated their participation level as “fair”, 51 percent of the respondents rated as “good, and 5 percent rated very good. Therefore, the researcher can conclude that only few (11 percent) of respondents have poor participation in the activities of their neighborhood. This may be due to different reasons not revealed in this research. Otherwise the participation of most respondents in their neighborhood is fair or good.

Responding to the question asked if there are things that they are unable to do in the community because of having children with clubfoot, 86 percent of the participants responded as “none”, 4.4 percent of the participants responded that they were unable to “move around easily, 4.4 percent of the respondents answered as “not being available when I am needed”, 4.4 percent responded that they are unable to work well. This shows that for most of the respondents having a club foot child didn’t prevent them from doing anything they want in their communities. Very low percentage of people (4.4 percent) revealed that because of their disabled child they were unable to move around easily, (4.4 percent) couldn’t be available when they are needed, and (4.4 percent) could not work well in the community because of a child with clubfoot.

With regards to the question asked if having a child with club foot deformity has an impact on the respondent’s relationship with the community, 4.4 percent of the participants responded as “Yes”, whereas 95.6 percent responded as “No”. Based on the major response of the respondents being “no”, we can conclude that having a child with

club foot deformity does not have an impact on the relationship of the majority of people with their communities.

Respondents were asked if they ever felt of being secluded from the neighborhood because of their club foot child, and 9 percent of the participants responded as “Yes”, and 91 percent responded as “No”. Therefore, the researcher can conclude that, being secluded from the neighborhood because of having a clubfoot child is very unlikely.

Likewise, the question asked if respondents ever faced discrimination in their communities because of their club foot child 2 percent of the participants responded as “Yes”, and 98% percent said “No”. This indicates that ever facing discrimination in community because of having a club foot child has no place.

#### 4.3.4. General Questions

Table 4.7: General Questions

	<b>Response</b>	<b>Frequency</b>	<b>Percent</b>
Anything that you couldn't accomplish for yourself because of club foot child.	None	40	89.0
	Raise my child appropriately	2	4.
	not putting on shoes for my child	2	4.4
	To Work	1	2.2
	Total	45	100
How would you rate the time you give for yourself	Poor	10	22.0
	Fair	13	29.0
	Good	22	49.0
	Total	45	100
Do you feel stressed out from taking care of a child with clubfoot deformity	Yes	34	76.0
	No	11	24.0
	Total	45	100
If yes, how would you rate the level of stress that you experience	Low	14	31.0
	Average	18	40.0
	High	8	18.0
	Very high	5	11.0
	Total	45	100
How do you get your stress relieved	Praying	4	9.0
	Chat with friends	12	27.0
	Relax	2	4.0
	Watch TV	2	4.0
	Nothing	22	49.0
	Support from spouse	3	7.0
	Total	45	100

Source: Own survey, 2018

Table 4.7 shows the result of respondent's response towards the questions asked. Respondents were asked if there was anything that they couldn't accomplish for themselves because of their club foot child. From the result obtained, we can see that 89 percent of the participants responded as "None"; 4% of respondents indicated as "raise my child appropriately", and "not putting on shoes for my child" has scored 4.4 percent; 2.2 percent revealed their inability to work because of their club foot child. The result indicates that the majority of the respondents (89 percent) do not have anything that they are unable to accomplish because of having a club foot child.

Respondents were asked to rate the time they give for themselves. 22 percent of respondents rated the time they give to themselves as "poor", 29 percent rated as "fair", and 49 percent of respondents has rated the time they give to themselves as "good". From this the researcher can conclude that the majority of the respondents give either good or fair amount of time for themselves.

A question was asked if the respondents feel stressed out from taking care of a child with clubfoot deformity. For this, 76 percent of respondents have scored "Yes" and 24 percent of respondents have scored "No". From this the researcher can conclude that most parents (75%) feel stressed out from taking care of a child with clubfoot deformity.

The respondent who responded "Yes" to the above question were asked to rate the level of stress that you experience. For this question, 31 percent of respondents have rated the level as "low", 40 percent of respondents have rated the stress level as "average", 18 percent of respondents rated as "high" and 11 percent of respondents rated the stress level being "very high". From this the researcher can say that the stress level of most of the parents (40%) is average or moderate.

The respondents were asked an open ended question to state how they get their stress relieved. From their response, we learned that 9 percent of the respondents get stress

relief by praying, 27 percent of the respondents get their stress relieved by chatting with friends, 4 percent stated that they get stress relief by relaxing, and 4 percent get their stress relieved by watching TV. The majority (49 percent) of the respondents do nothing for stress relief. This shows that while some of the respondents get their stress relieved through praying and chatting with friends, others do not do anything. They just live with the stress.

#### **4.4. Qualitative analyses: In depth Interview with Parents/caregivers**

Besides obtaining data from questionnaires, in depth interview was held with parents/caregivers who volunteered to take part in the study. The table below shows their background information:

**Table 4.8: Interview respondents' profile**

<b>Respondent No.</b>	<b>Place of residence</b>	<b>Sex</b>	<b>Age</b>	<b>Education Level</b>	<b>Marital Status</b>	<b>Employment</b>	<b>Age of the child</b>	<b>No. of children at home</b>
<b>1</b>	Afar	M	19	12 <sup>th</sup>	Single	Student	1yr	4
<b>2</b>	A.A.	F	29	7 <sup>th</sup>	Married	Unemployed	2yrs	-
<b>3</b>	A.A.	F	27	6 <sup>th</sup>	Separated	Unemployed	1mon	1
<b>4</b>	Oromia Special zone	M	42	Degree	Married	Self employed	3 &1/2 yr.	2
<b>5</b>	A.A.	M	32	8 <sup>th</sup>	Married	Employed	3 mon	-
<b>6</b>	A.A.	F	25	10 <sup>th</sup>	Separated	Unemployed	5 mon	-
<b>7</b>	Ambo	M	37	Illiterate	Married	Employed	3 mon	2
<b>8</b>	Oromia	F	30	Diploma	Married	Self employed	3 mon	1
<b>9</b>	Oromia	F	24	Diploma	Married	Employed	2 mon	1
<b>10</b>	N. Shoa	M	67	8 <sup>th</sup> Grade	Married	Employed	3 mon	3



## **Summary of results in the qualitative study:**

Respondent # 1: He is 19 years old, and a 12<sup>th</sup> grade single student. He came to the clinic from Afar accompanying his aunt who has a club foot child. He is the primary person who takes care of the child in his treatment. His aunt lives in a country side. The family didn't know about clubfoot before. He said:

*“People in the community thought that clubfoot will get better through time as the child grows, and there is nothing that could be done about it. When one of our relatives whose son had the same problem told us that it is curable, and he gave us information to come here for treatment.”*

The family did not think club foot was such a problem. Regarding relationships, he said that his aunt has a very good relationship with the community, and participates in all activities. They live a nomadic life, and they have good support for each other. Others in the surrounding take care of the child, 1 year old, when she goes to fetch water. Also, her older children help her out. People in the community do not see clubfoot deformity differently. With regards to challenges in following up with the treatment, his problem is missing his classes when he travels to Addis. He stated that he spends up to 2000 birr every week to travel long distance, but didn't say that finance was a problem.

Respondent # 2: This is a 29 years old female married participant, unemployed, educated up to 7<sup>th</sup> grade. She lives in Addis Ababa. The woman gave birth in at a health center, but no one noticed that the child has clubfoot until she noticed 15 days later and sought after treatment. She said that she was so sad when she saw that her baby's feet were deformed, and didn't think that it had any hope. She said, *“We kept silent saying that it was from God”*. None of the family had awareness about clubfoot before.

Regarding her relationships with others, she has good relationship with her neighbors, but she does not participate in any activities in the community. She lives in a rented house and is new to the surrounding. As for what the community says, she said that, *“I do not want to show my child to others; they think that I am cursed, but later they understood about it, there are many worse conditions than this”*.

As for what the community says, she said that, *“I do not want to show my child to others; they think that I am cursed; later they understood about it, there are many worse conditions than this”*.

Her challenge is financial. She cannot work, because there is nobody who helps her with child care and follows up with her child’s treatment. She described her situation as, *“life is difficult for me; I want to work and change my life.”*

Respondent # 3: This is a 27 years old female, living in Addis Ababa. She is separated from her husband, and is unemployed. She didn’t know about clubfoot before until she bore a child with the deformity. The baby she brought with her was only 1 month. She gave birth in a hospital, and said she was devastated when she saw her child with club foot. She got information at the hospital that it was curable, and referred her to Black Lion hospital.

Regarding relationships with others in the family, she got tearful; she said sadly, *“my husband left me when he knew I was pregnant. I don’t know where he is now; he has switched off his phone”*. She has a fair relationship with her neighbors and the community, and no one knows about the problem that my child has. Her challenge is to come every week for treatment- it has been only one month since she gave birth in a C-section, and she hasn’t fully recovered.

Respondent # 4: This is a 42 years old male, married, and self employed. He resides in Sululta, Oromia special zone. He brought his 3 ½ years old son to the clinic. He didn't know about clubfoot before his child was born with it. He said that he and his family were shocked at first, but got relieved when the health care professionals told them that it can be treated. The family accepted it saying that is "God's work".

Regarding relationships, he said that he has a good relationship with the neighborhood community, and participates in its activities. Regarding the perception of the community about clubfoot deformity, they ask him questions "*why did it occur?*" He said that he didn't want the neighbors to know about it.

His challenge in following up with the treatment shortage of transportation to come to the clinic and lack of time. He had to go out to a very far place for work, and did not follow up with their child's treatment for 5 months. His wife works as well, and could not get time off. He understands very well that the treatment won't be successful if he didn't follow up.

Respondent #5: This is a 32 years old male, married, educated up to 8<sup>th</sup> grade, and works in an organization as a guard. He lives in Addis Ababa. He didn't know about clubfoot deformity before his baby, 3 month now, was born with it. He said that he was shocked when he was born, but the doctors and nurses comforted and gave him hope when they told him that it was a curable condition. And they referred him to Black Lion hospital for treatment.

Regarding relationships, he has good support from his relatives. They give him comfort saying that my baby will be cured because "*his bone is soft*". He does not participate in any activities in the community. In his words, he said:

*“I do not have a good social life, because it requires money. My wife doesn't work in order to take care of the baby. I work two jobs to support my family. I do not have paid time off from work, today I may have a salary cut because I missed work”.*

The challenge that he has in following up with the treatment is the high desire of his wife to go away to see her family and stay for a little while. He said,

*“I do not want the baby's treatment interrupted; even if it is interrupted, it will not be good for him to travel in a cast; he should at least be 6 months; it has been an ongoing argument with my wife”.*

Respondent# 6: This is a 25 year old female who is with her 5 month old baby. She is educated up to 10<sup>th</sup> grade, and is separated from her husband. She gets assistance from the government's “safety net program”. She didn't have awareness about the occurrence of clubfoot before. She expressed how she felt about it at first as, *“I was sad; I didn't think that it was treatable, but the staff at the hospital gave me comfort; they told me that it can be cured”.*

She has good support from her close family, but not from the baby's father who she lived for 4 years. She was tearful when she narrated her relationship with him:

*“He left me alone when I reached 9 months in my pregnancy; he told me that he was going to bring food supplies that would help me when I give birth. But he didn't come back. His family lives out of Addis Ababa, and they wanted me to go and join him, but I didn't want to. They are many in number; they do not know that I gave birth to a baby like this”.*

Regarding relationships with the community, she participates in major activities. Her neighbors, with the exception of her roommate, do not know that she bore a child with

club foot. She doesn't want anyone in the neighborhood to see her baby's feet. She stated, *"It is because I didn't want them to give me a derogatory name"*. Her challenge in life is not able to work because of her child. She hopes to work when the child gets cured.

On the other hand, all of the rest of the participants in the interview (no. 7 to 10 in table 4.8) stated that they didn't have any knowledge about clubfoot, and that they were shocked to see their club foot child for the first time. But they were comforted that club foot was curable. All have good relationship with their family and the community except respondent # 8, a 30 year old mother who said that she was new to the community; neither has she had good family support because she doesn't live close to them.

Regarding challenges the four respondents may have with regards to the club foot treatment, all stated that they come from long distances for the treatment, and that incurs high transportation cost to them. All said that leaving their work to come to the clinic every week was difficult for them. Respondent # 10, a 62 year old man taking care of his grandson stated that his wife was not able to work on her small business because of the child. With regards to discrimination or seclusion that may occur due to the children's disability, all of the four respondents said they were none. But, respondent # 10 revealed his assumption as: "the family of the child's father hasn't seen the child, and I felt sorry for that; I think it is because of the child's condition". In general, all of the respondents shared that the deformity of the child didn't have negative impact on the family.

As we can understand from the words of the participants, they were shocked or sad when they gave birth to children with club foot, because they didn't have prior knowledge about the condition. Four of the families interviewed had their children born at health centers and were immediately referred to the Black Lion hospital for treatment. The deformity of one child was missed even if he was born in a health care setting. Knowing that club foot can be cured, they have accepted it. From the interview, we can understand

that there is a tendency not to expose the clubfoot children for others to see them in fear of what others say or ask about the deformity.

The treatment for clubfoot requires that families come once a week for casting, for 6 to 8 weeks depending how fast the foot is corrected. The staff in the clinic makes sure that they take the treatment seriously, because if they miss the treatment the feet won't be corrected. The participants have their own challenges on following up with the treatment. One of the challenges is missing work due to the follow up process. The other challenge for those parents/caregivers that have to travel long distance is the financial burden of transportation cost.

## **CHAPTER FIVE**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1. Conclusions**

This chapter attempts to summarize the main findings of the research. It is essential that professionals including social workers, health professionals and other concerned bodies including government officials understand the challenges of families having children with club foot disabilities. This study has documented the real and ongoing challenges of these families.

It is possible to say that most of the families that come from distant places to follow up with their children's club foot treatment at Black Lion hospital face financial problem to cover their transport costs. The treatment at the hospital is free of charge. The treatment requires for the children to follow up every week for the application of cast to correct club foot deformity. After the deformity is corrected, the children are given shoe braces to wear. Then, they won't have frequent follow ups, but at spaced intervals to make sure that the intervention worked. The other challenge mentioned by those who are employed is that they have challenges to get off work for the treatment of their children. Of the respondents, eighty percent said the treatment interfered with their work, where they are employed by others or are self employed. Most families come from Addis Ababa and Oromia special zone. There are 32 club foot clinics in different regions of Ethiopia, and families bring their children to the nearest club foot clinic.

Regarding the relationship of families with club foot children with others, the research revealed that to the most part, they have good relationship with their relatives, neighbors and the community. The majority gets good support from their close relatives. Mostly,

both parents come for follow up together, and this shows the support they get for each other, the study confirmed that. The results of the study showed that although families have challenges in taking care of their club foot children; the family integrity is not affected because of having club foot children. The number of respondents who said that the family integrity is weakened is insignificant (7 %).

On the other hand, the study revealed that most parents were shocked when they bear children with club foot. But, with the support and comfort that they received from the health care professionals, they were hopeful that their children can be cured. Immediately, they got referred to Black Lion hospital for treatment. The club foot treatment starts at the age of one month. With regards to the existence of discrimination or seclusion in the community concerning their children's disability, it is not conclusive. Other studies show that families with children having deformity face seclusion and discrimination, especially when the children are out in the public. From the qualitative study the researcher conducted, there is evidence that people are not disclosing their children's disability in fear of labeling and stigma. Because the children are very small, it is easy to cover up with clothes so that no one could see.

## **5.2. Recommendations**

- It is encouraging that there are 32 club foot clinics in the different regions of Ethiopia. However, the researcher suggests expanding club foot clinics to different areas of the country in collaboration with regional hospitals. In fact, it calls for capacity building of the staff to treat club foot, and requires resources to do that. In doing so, children diagnosed with club foot get treatment at their vicinity than traveling long distances. This would shorten the travelling distance for parents. Also, It increases the accessibility of these services to the poor that



are unable to meet transportation costs, and it would be an effective strategy of taking services near the people.

- Families are advantaged to get club foot treatment free of charge. Even with this free service, some are challenged with the treatment cost. It is recommended that governmental or non governmental institutions offer financial assistance to the very poor that is struggling with transportation costs.
- There is a need to enhance a health education program for parents at the Black Lion hospital club foot clinic. This will increase awareness among parents about clubfoot and the treatment process and explain the importance of following up on the appointment dates for a positive outcome. This can be implemented through the use of health education talks to be provided to parents as they wait for treatment in the waiting room. This can be an effective strategy of providing information to parents, as it requires few resources.
- There needs to be training conducted at the health centers in the communities to create awareness on childhood disabilities. The study identified that none of the respondents had prior knowledge of club foot deformity.
- The researcher also recommends that more research that involves both qualitative and quantitative approaches be done on the same topic at other club foot centers located in other regions of Ethiopia to assess the family life of children with club foot deformity. This could capture data and views of parents in different settings, which could be used to develop programs that could improve the treatment of clubfoot in Ethiopia. Also, it could serve as literature for future policy development related to health issues.

- More research is needed to further understand the extent to which the parents who are providing care for their disabled children's are affected, and how they are affected by their responsibilities on the care they provide to the children. Furthermore, the researcher suggests that forthcoming studies focus on the psychological and psycho-social impacts of children's disabilities on the parents.

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## **ANNEXES**

### **Annex 1: Questionnaire for parents/caregivers**

Indira Gandhi National Open University (IGNOU)

Department of Social Work

Dear respondents,

First of all my sincere gratitude goes to you. I am working on my thesis for my Masters in social work with Indira Gandhi National Open University (IGNOU) at Saint Mary University and the title of my research is: “**Assessment of Children’s Physical Disability Family Life**”. I conduct the research as partial fulfillment of the Masters of social work **Indira Gandhi National Open University (IGNOU)**.

The results of the study will be used as a guide to assessment of children’s physical disability family life. I kindly request your participation in this study by completing the questionnaire according to the statements given. The participation is voluntarily and the information given will be confidential. My Contact Address: +251912178708 or email address: tiflemm@yahoo.com

**Thank You in Advance for Your Cooperation!!**

It is hoped that the information you will give in this study will be helpful in planning for improving children’s physical disability family life.

**Instructions: Please do NOT write your name on this questionnaire.**

Please select one response by circling the number of your choice.

Name of the person filling out the form: \_\_\_\_\_ Signature: \_\_\_\_\_

Questionnaire number: \_\_\_\_\_

## Questionnaire for parents/caregivers

### Background Data

1. Sex            1. Male            2. Female

2. What is your current marital status?

1. Single            2. Married            3. Divorced            4. Widowed

3. Place of residence: Region \_\_\_\_\_ 1) urban 2) rural

4. Age:            1) 18-25            2) 26-35            3) 35-45            4) Above 45

5. What is your employment status?

1. Employed            2. Self-employed            3. Unemployed            4. Housewife

5. Retired            6. Student

6. Education level

1. Illiterate            5. Technique & Vocational  
2. Read and write only            6. Higher education (diploma &  
3. Primary (1-8)            above)  
4. Secondary (9-12)

7. Person who brought the child to the hospital:

1. Father            2. Mother            3. Grandparent            4. Others- specify -----

8. The child's age: 1) Less than 6 Months            2) 6 Months to 1 year            3) 1 year and above

9. How long has your child been following up for the treatment of club foot? \_\_\_\_\_



10. Do you attend to treatment regularly?                      1. Yes                      2. No
11. What difficulties do you have in following the prescribed treatment?
- 11.1. Is it very expensive to attend treatment?                      1. Yes                      2. No
- 11.2. Do you have the time to attend to treatment every week?                      1. Yes                      2. No
- 11.3. Do you have anyone to leave other children with at home?                      1. Yes                      2. No
- 11.4. Is your home very far from the hospital to make it every week                      1. Yes                      2. No
- 11.5. If you work, does the treatment process interfere with attending to your work?                      1. Yes                      2. No
- 11.6. Please mention if you have any other problem. \_\_\_\_\_

**Questions on family relationships:**

12. What is your relationship been like with your spouse after your child was born with clubfoot deformity?
1. It has strengthened    2. It has weakened    3. No change    4. Spouse not around
13. How would you rate the support you get from your spouse with regards to caring for your child with club foot?
1. Poor    2. Fair    3. Good    4. Very good
14. How would you rate the support you get from your close relatives with regards to caring for your child with club foot?
1. Poor    2. Fair    3. Good    4. Very good
15. How would you rate your participation in your family's day to day activity?
1. Poor    2. Fair    3. Good    4. Very good
16. How would you rate the time you give to your family in your house?
1. Poor    2. Fair    3. Good    4. Very good
17. Is having a clubfoot child been a challenge in your family?    1. Yes    2. No

18. If the answer to the above question is yes, what is the challenge?

\_\_\_\_\_

**Questions on social life**

19. How would you rate your relationship with people in your community?

1. Poor 2. Fair 3. Good 4. Very good

20. How would you rate your relationship with your neighbors?

1. Poor 2. Fair 3. Good 4. Very good

21. How would you rate your participation in the activities of your neighborhood?

1. Poor 2. Fair 3. Good 4. Very good

22. Is there anything that you are unable to do in your community because of having a child with club foot? 1. Yes 2. No

23. If yes, what is it? \_\_\_\_\_

24. Does having a child with club foot has impact in your relationship with the community? 1. Yes 2. No

25. If the answer to the above question is yes, what is the social impact?

\_\_\_\_\_

26. Have you ever felt of being secluded from the neighborhood because of having a child with club foot deformity?

1. Yes 2. No

27. Have you ever faced discrimination in your community because of having a child with club foot?

1. Yes 2. No

**General questions**

28. Please state if there anything that you couldn't accomplish because of having a child with clubfoot deformity. \_\_\_\_\_

29. How would you rate the time you give for yourself?

1. Poor 2. Fair 3. Good 4. Very good

30. Do you feel stressed out from taking care of a child with clubfoot deformity?

1. Yes 2. No

31. If the answer to the above question is yes, how would you rate the level of stress that you experience?

1. Low 2. Average 3. High 4. Very high

32. How do you get your stress relieved? \_\_\_\_\_

**THANK YOU FOR YOUR COOPERATION**

## **Annex 2: Consent for Interview schedule**

My name is Tifsehet Lemma. I am a student of **Indira Gandhi National Open University (IGNOU)** studying for my Masters in Social Work. Currently, I am working on my thesis, and it is concerning the family life of club foot children. The objective of the study is to learn if the challenges that families may have. To do this, I will ask you questions. Your participation will be voluntary. The data collected will help as a resource to a study on the university's knowledge.

In order to get accurate data, the interview will be recorded. Names of the interviewer and any related personal data will not be included in the study. Also, the data in this study will remain confidential. You have a right to withdraw from this interview, and you can withdraw from this interview at anytime.

The content of this study can be provided to you upon your request.

I declare my agreement to participate in the interview by signing below:

Name: ----- Signature: -----

### **Annex 3: Interview Guide for parents/caregivers**

1. Please tell me your background information (age, work, marital status, place of residence, other children)
2. Tell me about your child you brought for treatment (age, when he was diagnosed with clubfoot, when he started treatment, who told you about this hospital)
3. Did you know about clubfoot before the child was born (what did you feel when the child was born with clubfoot, what did others say- spouse, family, relatives, neighbors, others in the community)?
4. Do you have any challenges in following up with the child's treatment? (shortage of transportation, financial problem, attending with work, leaving children behind, distance of hospital to home? transport cost?)
5. How do you see your relationship with your family (spouse, other children, close relatives)?
6. How do you see your relationship with your neighbors (do you visit each other)?
7. How do you see your relationship with your community (do you participate in social obligations, do you have enough time to do so)?
8. Does bearing a clubfoot child has any impact on the family (strengthened the relationship, weakened, or there is no change.
9. Have you ever experienced discrimination or seclusion because of your clubfoot child (feeling shame)?
10. Is there anything that you worry about your child having clubfoot?

Annex 4

Questionnaire for parents/caregivers in Amharic

በቅድስተ ማርያም ዩኒቨርሲቲ

የኢንድራ ጋንዲ የርቀት ዩኒቨርሲቲ የድህረ ምረቃ ጥናት

የማህበራዊ አገልግሎት ጥናት ክፍል(ሶሻል ወርክ)

መጠይቁን ለትሞሉ ሰዎች በሙሉ:-

በመጀመሪያ ይህን መጠይቅ ለመሙላት በመተባበርዎ ምስጋናዬ ይድረስዎት። ስሜ ትፍስህት ለማ ይባላል። በቅድስተ ማርያም ዩኒቨርሲቲ ለማህበራዊ አገልግሎት ጥናት የመመሪያ ጽሁፍ የአካል ጉዳተኛ ቤተሰቦችን የቤተሰብ ሕይወት በተመለከተ የዳሰሳ ጥናት በመስራት ላይ እገኛለሁ። ይህንንም ጥናት የማካሄደው የኢንድራ ጋንዲ የርቀት ትምህርት (ኢግኑ) የሶሻል ወርክ ድህረ ምረቃ ጥናት ክፍል የማሟያ መስፈርት በመሆኑ ነው ።

የዚህ ጥናት ውጤት የአካል ጉዳተኛ ቤተሰቦችን የቤተሰብ ሕይወት ዳሰሳ በተመለከተ አመለካኝ መንገድ ይሆናል። ስለሆነም በዚህ መጠይቅ ውስጥ የሚገኙትን ጥያቄዎች በመሙላት ተሳትፎ እንዲያደርጉ ትብብር እጠይቃለሁ። ተሳትፎውም በፈቃደኛነትዎ ላይ የተመሰረተ ሲሆን የሚገኘው መረጃም ምስጢሩ የተጠበቀ ይሆናል። የምገኝበት አድራሻ፡ ስልክ 0912178708፤ ኢሜይል [tiflemm@yahoo.com](mailto:tiflemm@yahoo.com)

ስለትብብርዎ በቅድሚያ አመሰግናለሁ።

እርስዎ በመጠይቁ ላይ የሚሰጡት መረጃ የአካል ጉዳተኛ ቤተሰቦችን የቤተሰብ ሕይወት ለማሻሻል ለማቀድ ይጠቅማል ተብሎ ይታመናል።



9. የታካሚው ልጅ እድሜ 1.ከስድስት ወር በታች 2. ከስድስት ወር እስከ 1 አመት 3. ከአንድ አመት በላይ

10. ልጅዎ የሕክምና ክትትል ከጀመረ ምን ያህል ጊዜ ሆነው?-----

11. ሕክምናውን በሚገባ ይከታተላሉ? 1) አዎ 2)አይደለም

12. ሕክምናውን ለመከታተል ሲያጋጥም የሚችል ችግርን በተመለከተ:-

12.1. በየሳምንቱ ክትትል ለማድረግ ወጪ ይበዛብዎታል?

1) አዎ 2)አይደለም

12.2. በየሳምንቱ ክትትል ለማድረግ በቂ ጊዜ አለዎት?

1) አዎ 2)አይደለም

12.3. እዚህ ክትትል ሲያደርጉ ሌሎች ልጆችዎን እቤት ውስጥ ጥለው ነው የመጡት? 1) አዎ 2)አይደለም

12.4. ቤትዎ ከሕክምና ቦታው በጣም ይርቃል?

1) አዎ 2)አይደለም

12.5. ስራ የሚሰሩ ከሆነ የሕክምናው ክትትል ስራዎትን በሚገባ እንዳያከናውኑ አድርጓል? 1.አዎ 2)አይደለም

12.6. ሌላ ችግር ካለ ይጥቀሱ -----

ከቤተሰብ ጋር ያለውን ግንኙነት በተመለከተ:-

13. ቆልማማ እግር ያለው ልጅ ከወለዱ በኋላ ከባለቤትዎ ጋር ያለዎትን የእርስ በርስ ግንኙነት በተመለከተ:-

1) ግንኙነቱ እንዲጠናከር አድርጓል

2) ግንኙነቱ ቀዝቅዟል

3) ምንም ለውጥ የለውም



14. የልጅዎን እንክብካቤ በተመለከተ የባለቤትዎን ድጋፍ እንዴት ይመዘኑታል?

1. ዝቅ ያለ/ ደካማ 2. መጠነኛ 3. ጥሩ 4. በጣም ጥሩ

15. የልጅዎን እንክብካቤ በተመለከተ የቅርብ ዘመዶችዎን ድጋፍ እንዴት ይመዘኑታል?

1. ዝቅ ያለ/ ደካማ 2. መጠነኛ 3. ጥሩ 4. በጣም ጥሩ

16. በቤተሰብዎ የእለት ከእለት እንቅስቃሴ ውስጥ ያለዎትን ተሳትፎ እንዴት ይመዘኑታል?

1. ዝቅ ያለ/ ደካማ 2. መጠነኛ 3. ጥሩ 4. በጣም ጥሩ

17. ለሌሎች የቤተሰብዎ አባላት የሚሰጡትን ጊዜ እንዴት ይመዘኑታል?

1. ዝቅ ያለ/ ደካማ 2. መጠነኛ 3. ጥሩ 4. በጣም ጥሩ

18. ቆልማማ እግር (ክለብ ፉት) ያለው ልጅ በመውለድዎ በቤተሰብዎ ላይ ጫና ፈጥሯል? 1. አዎ 2. የለም

19. መልስዎ አዎን ከሆነ ጫናው ምንድነው-----

**ማሕበራዊ ግንኙነትዎን በተመለከተ**

20. ከአካባቢዎ ሰዎች ጋር ያለዎትን ግንኙነት እንዴት ይመዘኑታል?

1. ዝቅ ያለ/ ደካማ 2. መጠነኛ 3. ጥሩ 4. በጣም ጥሩ

21. ከጎረቤቶችዎ ጋር ያለዎትን ግንኙነት እንዴት ይመዘኑታል?

1. ዝቅ ያለ/ ደካማ 2. መጠነኛ 3. ጥሩ 4. በጣም ጥሩ

22. በሰፈር ውስጥ በሚደረጉ አንቅስቃሴዎች ላይ ያለዎትን ተሳትፎ እንዴት ይመዘኑታል?

1. ዝቅ ያለ/ ደካማ 2. መጠነኛ 3. ጥሩ 4. በጣም ጥሩ

23. ልጅዎ ቆልማማ እግር ኖሮት በመወለዱ ምክንያት በማህረሰቡ ማከናወን ያልቻሉት ነገር ካለ ይጥቀሱ-----

24. ቆልማማ እግር (ክለብ ፉት) ያለው ልጅ በመውለድዎ ከማህረሱ ጋር ባለዎት ግንኙነት ላይ ጫና ፈጥሯል?

- 1. አዎ            2. የለም

25. መልስዎ አዎን ከሆነ ማህበራዊ ጫናው ምንድነው-----

26. ቆልማማ እግር ያለው ልጅ በመውለድዎ ምክንያት የአካባቢው ሰው እርስዎን የማግለል ሁኔታ አጋጥሞዎት ያውቃል? 1. አዎ    2. የለም

27. ቆልማማ እግር ያለው ልጅ በመውለድዎ ምክንያት ሰዎች አድልዎ አድረሰውብዎት ያውቃል?    1. አዎ            2. የለም

**አጠቃላይ ጥያቄዎች:-**

28. ቆልማማ እግር ያለው ልጅ በመውለድዎ ምክንያት በግልዎ ለማከናወን ያልቻሉት ነገር ካለ ምንድነው-----

29. ለእራስዎ የሚሰጡትን ጊዜ እንዴት ይመዘኑታል?

- 1. ዝቅ ያለ/ ደካማ    2. መጠነኛ    3. ጥሩ    4. በጣም ጥሩ

30. የአካል ጉዳት ያለውን ልጅ መንከባከብ በሕይወትዎ ላይ የአእምሮ ጫና (ጭንቀት) አሳድሮብዎታል?

- 1. አዎ            2. የለም

31. መልሱ አዎን ከሆነ የአእምሮ ጫናውን (ጭንቀቱን) እንዴት ይመዘኑታል?

- 1. ዝቅተኛ    2. መጠነኛ    3. ከፍተኛ    4. በጣም ከፍተኛ

32. ለአእምሮዎ እረፍት የሚያገኙበት መንገድ ካለ ይግለጹ:- -----

**ስለ ትብብርዎ አመሰግናለሁ።**

**Annex 5: Consent for Interview schedule**

**ለቃለ መጠይቅ የመስማሚያ ሰነድ**

ስሜ ትፍስህት ለማ ይባላል። በኢንድራ ጋንዲ የርቀት ዩኒቨርሲቲ የማሕበረሰባዊ ሥራ ጥናት (የሶሻል ወርክ) የድህረ ምረቃ ተማሪ ነኝ። ለመመረቂያ ፅሁፌ ጥናት በማካሄድ ላይ እገኛለሁ። የጥናቱ ርዕስ ቆልማማ እግር ያላቸው ቤተሰቦች ሕይወትን በተመለከተ ነው። የጥናቱ አላማ ይህ ጉዳት ያለባቸው ቤተሰቦች ሊያጋጥማቸው የሚችል ችግር ካለ ለመረዳት ሲሆን ይህን ለማድረግም ይህን ቃለመጠይቅ እጠይቅዎታለሁ። የእርስዎ ተሳትፎ በፈቃደኝነት ላይ የተመሰረተ ይሆናል። የሚሰበሰው መረጃ በዩኒቨርሲቲው እውቅና ሌሎች ተመሳሳይ ጥናቶችን ለማጥናት ይረዳል።

ቃለ መጠይቁ ትክክለኛውን ሃሳብ ለመያዝ ሲባል በቴፕ ይቀዳል። ስም ወይም ሌሎች ተያያዥ መረጃዎች ፅሁፉ ውስጥ የማይካተቱ ሲሆን ከዚህ ቃለ መጠይቅ የሚገኘው መረጃም በምስጢር ይጠበቃል። ከዚህ ቃለ መጠይቅ እራስዎን የማግለል መብት ያለዎት ሲሆን፣ ተሳትፎዎንም በማንኛውም ጊዜ መሰረዝ ይችላሉ።

የጥናቱ ጥቅል ሃሳብ በጥያቄዎ መሰረት ሊሰጥዎ ይችላል።

ከላይ በተገለፀው ሃሳብ መስማማቱን በፊርማዬ አረጋግጣለሁ።

ስም:- .....

ፊርማ:- .....

ቀን:- .....

Annex 6

Interview Schedule with Parents/caregivers in Amharic

ለወላጅ/አሳዳጊዎች በአማርኛ የተዘጋጀ ቃለ መጠይቅ

1. ስለእራስዎ ቢነግሩኝ (የት እንደሚኖሩ፣ ገጠር ነው ወይስ ከተማ? እድሜ፣ ስራ፣ የጋብቻ ሁኔታ፣ የትምህርት ደረጃ፣ ሌሎች ልጆች ካሉ፣ ወዘተ.)
2. ከእርስዎ ጋር ስለመጣው ልጅዎ ሁኔታ (እድሜ፣ ችግሩ መቼ እንደታወቀ፣ ክትትል መቼ እንደጀመረ፣ ወደ ሆስፒታል እንዲሄዱ ማን ነገርዎት?)
3. ስለቆልማማ እግር ምን ያውቃሉ (ከመወለዱ በፊት፣ ከተወለደ በኋላ የባለቤትዎ፣ የቤተሰብዎ፣ የዘመዶችዎ፣ የጎረቤቶችዎ፣ የማህበረሰቡ አስተያየት ምን ይመስላል?)
4. ክትትል ለማድረግ ምን ችግር ያጋጥምዎታል (የትራንስፖርት እጦት፣ የገንዘብ እጥረት፣ የሥራ መጓደል፣ ልጆች ጥሎ መምጣት፣ ለትራንስፖርት ብዙ ያወጣሉ? ስንት ያወጣሉ? ከቤትዎ እርቀት አለው)
5. ከቤተሰብዎችዎ ጋር ያለዎት ቅርበት ምን ይመስላል (ከባለቤትዎ፣ ከሌሎች ልጆችዎ፣ ከቅርብ ዘመዶችዎ ጋር)?
6. ከጎረቤቶችዎ ጋር ያለዎት ቅርበት ምን ይመስላል? (ትጠያየቃላችሁ?)
7. ከማሕበረሰቡ ጋር ያለዎት ቅርበት ምን ይመስላል? (እድር፣ ማሕበር፣ ሰርግ፣ ለቅሶ፣ ወዘተ፣ ቅርበት ምን ይመስላል? ለመሳተፍስ በቂ ጊዜ አለዎት?)
8. ቆልማማ እግር ያለው ልጅ በመውለድዎ ቤተሰብዎ ላይ ምን አይነት ተፅእኖ አሳድሯል (ቤተሰቡን አጠናክሯል/ ጎድቶታል/ምንም ተፅእኖ አሳሳደረም? ሌሎች ልጆች ካለዎት ለእነርሱ በቂ ክትትል እንዳያደርጉ አግዷል?)
9. በልጅዎ ምክንያት አድልዎ/ መገለል ደርሶብዎት ያውቃል (እንዲሳቀቁ የማድረግ ሁኔታ፣ ገሸሽ ማድረግ፣ የሚገባዎትን ነገር መንፈግ፣ ወዘተ)?
10. ልጅዎ ቆልማማ እግር ያለው በመሆኑ የሚያስጨንቅዎት ነገር ካለ ቢነግሩኝ?