ADDIS ABABA UNIVERSITY SCHOOL OF GERADUATE STUDIES
COLLEGE OF EDUCATION AND BEHAVIORAL STUIES
DEPARTMENT OF SPECIAL NEED EDUCATION

THE ROLE OF MOTHERS WITH CP CHILDREN IN REHABILITATION CENTER TO SUPPORT CHILD WITH CEREBRAL PALSY IN CHESHIRE ETHIOPIA

BY
MESFIN ENDALE

ADVISOR: ALEMAYEHU T. (PH. D)

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This is to certify that the thesis prepared by Mesfin Endale , entitled: The role of mothers in rehabilitation center to support child with cerebral palsy in Cheshire Ethiopia and submitted in partial fulfillment of the requirements for masters of degree of in special need education meets the accepted standards with respect to originality and quality.

1. ADVISOR

NAME _____SIGNATUER _____ DATE_____

2. INTERNAL EXAMINER

NAME _____SIGNATURE _____ DATE_____

3. EXTERNAL EXAMINER

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Abstract

This study was conducted aiming to explore the role of Mothers of Children with cerebral palsy Cheshire Ethiopia rehabilitation Center in Addis Ababa. The study specifically focused the role, perception and challenges of mothers in rehabilitation center. Descriptive qualitative study type approach was used to explore the lived experience of mothers of children with cp and semi-structured interviews were applied with five mothers of children with simple random sampling technique was implemented. FGD and observation were also used for data collection.

Findings of the study indicated that mother of children living with cerebral palsy involved in the rehabilitation center. They were challenged by lack of financial support, transport and physical treatment training for mother of children with cerebral palsy. Results also pointed out that the effects of those challenges in mothers of children with cerebral palsy life such as psychological injurers, emotional disturbance, and financial problem. Findings provide detailed information and used as indicator of the need for further research on the role of mothers children with cerebral palsy in the rehabilitation center. The results of this study also hoped to give information and direction for researchers, rehabilitation center, policy makers, planners what should be done in the future and take measures to reduce their lifelong challenge.

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Abbreviations

ADL: Activity Daily Living

CBR: Community Based Rehabilitation

CP: Cerebral Palsy

CE: Cheshire Ethiopia

CSA: Central Statistical Agency

FGD: Focus Group Discussion

ILO: International Labor Organization.

JICA: Japan International Cooperation Agency

MDT: Multi-Disciplinary Team.

MOLSA: Minster of Labor and Social Affair

NPAPWD: National Plane of Action Persons with Disability.

UNCRPD: United Nations Convention Right of Persons with Disability.

UNESCO: United Nations Educational, Scientific and cultural organization.

MOE: Ministry Of Education

MOH: Ministry of h Health

Chapter One

1. Introduction

Numerous obstacles for mother of children with cerebral palsy and creates its own deep sorrow and trauma, “psychological, physical health and socio-economic challenges” throughout her life. Even though, mother plays essential role in the rehabilitation Center to care their children.(Glasscoe et al. 2007; Sajedi et al. 2010).

Furthermore, a mother has many hindrances in life such as maternal problems, lack of job opportunities on top of these nurturing and supporting children with disability (Borst, 2010).Therefore, It negatively touches the life cycle a mother of children with cerebral palsy (Olawale, Deih&Yaadar 2013; Yilmaz et al. 2013).

As a matter of fact, this study has an intention of assessing the role of mother of children with cerebral palsy in rehabilitation center, particularly in Cheshire Ethiopia. This section of the study contains the introduction part of the study which includes background of the study, statement of the problem, objectives of the study, significance of the study, scope of the study, limitation of the study, organization of the study, methodology,result, recommendation and conclusion.

1.1Background of the study

Disability may impairment, participation restriction, actively limitation and in this area different organization may have their own explanation and also the name is repeatedly talking in our daily dialogues with different meanings for different communities.According to United Nation United Nation Convention Rights Persons With disability (UNCRPDs) persons with disabilities considers

"those who have long- term physical, mental, intellectual, or sensory impairments which cause with various barriers that may hinder their full and effective participation in society on an equal basis with others".

In this regards, there is no single mostly agreed explanation given to the concept of disabilities. There is also small piece of information and concepts on the 'occurrence', distribution and experience of disability. For instance, World Health Organization pointed out that disability is "complex, dynamic, and multidimensional" (WHO, 2011). As a concept and definition disability is widely different.

In Ethiopia Persons with disability are perceived as "weak", "hopeless", "dependent", and "unable to learn" and "subject of charity". The misunderstandings and miscalculations of the abilities of persons with disabilities have contributed to experience low social and economic status (Tirussew, 2005).

The meaning of disability is different and its category is also different. Physical disability is one of the most common types of disability. It's associated with disorder such as, musculoskeletal, Nero-muscular disability, circulatory, respiratory and nervous system. In this group of classification there are primarily two groups of physical disability musculoskeletal disability and Nero-muscular disability (Tirstwold, 2018).

Musculoskeletal disability is incapability only one of its kinds of movement of the body parts due to bone deformity, which affect ligaments, joints, muscles, tendons, peripheral nerves, degeneration.But Nero-muscular disability is motor neuron diseases injury have an effect on body part due to diseases without controlled movement of degeneration disorder of the nervous system.(Ibid).

Cerebral palsy may begin in the early childhood extended throughout one's life. It is mainly associated with "disorder of sensation, behavior, motor speech, and"other cognitive impairments perception, cognition, communication, and behavior;" by epilepsy, and by secondary musculoskeletal problems" (Ibid)

Rehabilitation is important that the rehabilitation centers ought to care children's with living cerebral palsy. It may take short or long term procedure. In addition it depends according to the severity, to sustain empowering persons with disabilities and "optimal physical, sensory, intellectual, psychiatric and / or social functioning levels, providing them with the tools to change their lives towards a higher level of independence" Tirusew, (2005) World Health Organization (1996) citedbyYeshimebete (2014)

Moreover, the participation of parents in the rehabilitation practices and different teaching methods of informal and formal educational programs have its own great contribution. Several studies exposed contractive outcomes to the development of children. (Fan & Chen, 2001; McConachie&Diggle, 2007)

As the result, Current literature explain that caring the child with long- lasting disorder become too difficult and have an intense impact on the physical health, psychological health and, ultimately, the wellbeing of the caregiver, usually the mother. As numerous parents "cope quite wellwith the increased demands of rearing child with a disability", (Eisenhower et al. 2005; Smith et al. 1993; Turnbull et al.2004).

One of the major rehabilitation centers for persons with disability in our country is Cheshire Ethiopia. The organization has 5 branch offices in our country. According to, Robert W. 2012; the

organization has launched its work before 54 years back. In this organization children with disability came from all parts of the country.

The Reed House which is found in Addis Ababa and one of the branches of Cheshire Ethiopia pediatric rehabilitation center. The center has launched its operation in October, 2010 and provides physical rehabilitation for children with developmental impairments especially CP children found in the capital and it is strongly working with different community based rehabilitation programs through which referral linkages are recognized to admit the children at the center for Rehabilitation services. Hence, the main purpose of this study is exploring in the case of the role of mother with CP child in the rehabilitation center to treating her child with cerebral palsy in Cheshire Ethiopia pediatric rehabilitation center in Addis Ababa.

1.2. Statement of the problem

Mother of children living with cerebral palsy has different responsibilities with difficulties for their day to day life expectancy to facilitate several needs of a child. In fact "Both parents (mother and father)" of a child living with disability share household tasks, burdens to protect their child. Mothers are exposed to numerous challenges besides their life to allow their children to continue "clinical services and therapies, possible intervention of skill training and educational settings" (Dunlap, Newton, Fox, Benito, & Vaughn, 2001).

Despite the fact that mothers who are regularly pretty close and sensitive for their children, how much more the proximity is quite crucial for a mother of a child with CP since the child needs her full day special treatment in addition to the regular household management. The mother certainly confers time, energy, empathy, a psychological wellbeing, financial strength, flexibility and readiness to cope up the challenges.

Consequently, 'Discrimination' and 'labeling' can cause trauma and foster negative attitude for the mother. However, Rehabilitation centers, other stakeholder and vast community members need to ensure a great deal of involvement in order to pay attention for mothers and for their children. If not, the conscience is imposed to put mothers to hide their children at home (Amosunetal. 1995).

Studies have pointed out the impact and significant role played by mothers of children with cerebral palsy are limited, especially with regard to care of infants shortly after birth and the role played in the occupational therapy interventions. Thus, there should be study to find out the role of mothers in rehabilitation center to treat children with cerebral palsy. The role of mothers of children with cerebral palsy participate in the physical therapy in rehabilitation center for their children with cerebral palsy are likely to develop more understanding into the impairments and abilities of their children, resulting in more realistic view of their child's potential in relations of daily functioning. Moreover, by participating in therapy, mother can become more skilled at taking care of their children. Eventually, this increases mothers' confidence in their own competence and reduces maternal stress (Peat, 1997 as cited in Yesimebete, 2014).

Even though number of studies have been conducted on challenges of parenting children with disability and parenting experiences of mothers in general, researches particularly focused on the life of mothers of children with CP in Ethiopian context are very limited and not in depth (Agnail et.al, 2017).

To be more specific, the study by Yeshimebet (2014) conducted at Cheshire, Menagesha rehabilitation center found that the center provides physical (medical), and educational, social and vocational rehabilitation services. The study also found that the perception and attitude of

parents of children with physical impairment regarding the causes of impairment was changed as a result of the work rehabilitation services.

Previously studies have been conducted in Cheshire Ethiopia Rehabilitation center in various areas however this study tried to deal with the role of mothers to support children with cerebral palsy in rehabilitation center. The researcher believes that this research was fulfilling the gap found between government, community and non-government organization in helping and understanding the need of mother and their children attempts to understand the deep-rooted factors, roles and challenges of mothers of children with CP treating in the rehabilitation center. Hence, this study is attempted to explore the role of mother of Children with CP to sustain rehabilitation therapy that provided at Cheshire Ethiopia Rehabilitation Center in Addis Ababa.

1.3 Objectives of the study

1.3.1 General Objective

The general objective of this study is to explore the role of mother of Children with CP to sustain rehabilitation therapy that provided at Reed House CheshireEthiopiaPediatric Rehabilitation Center in Addis Ababa.

- The major objective of the study is to unfold the impediments, demonstrate the potential solutions and pave a way for other researchers to support mothers of children with cerebral palsy children specifically, with “community members, government and non-government organizations”

1.3.2 Specific Objectives

The specific objectives of this study are:

- To identify the role of mothers of child with CP during Rehabilitation therapy rehabilitation center.
- Investigate causes behind the role of mothers of children with cerebral palsy in their life.
- Identify handling mechanisms of mothers of children with cerebral palsy.
- Identify the current needs and future objectives of mothers of children with cerebral palsy.

1.3.3Research Questions

This study attempted to answer the following research questions:

1. To identify the role of mothers of child with CP during Rehabilitation andto sustain physical therapy.
2. Identify the major challenge of mothers of children with cerebral palsy during rehabilation.
3. Identify the perception of mothers of children with cerebral palsy.

1.4. Significance of the study

This research would help provides insight about to identify the role of Mothers' of Children with CP in order to sustain the rehabilitations with home base care services. Rehabilitation is not a short time activity;it needs the collaboration of different professions and has different cost Community work planners, organizations, and associations working on persons with disability, rehabilitation center more over the research work will help the concerned bodies in policy formulation, services providing procedures and in creating sustainable and inclusive

rehabilitation service for the community and contribute their efforts for the better life of the targeted population in general.

1.5. Delimitation of the study

Thedelimitations of this research study was unmeet plan to get additional information from other individuals working on disability in other organizations due to very tight schedule to meet them during working hours and arrange time for interview. The researcher also acknowledges that the limited number of literatures directly related to the research topic. Many of these study findings are focused one either mothers of children with disability in general or mothers of children with cerebral palsy.

1.6. Operational definitions of key terms

Cerebral palsy -is a type of disability characterized by limitations in physical and mental functioning.

Rehabilitation- It takes a long term procedure to come to the normal Position.

Role- Actively participates in the rehabilitation Center.

1.7. Organization of the thesis

This study is organized in to five chapters. The first chapter contains background of the study, statement of the problem, research questions,and objectives of the study, significance of the study, delimitations of the study and operational definitions of key concepts. The second chapter dealt with the literature review. The third chapter considers the research design and methodology. The fourth chapterdeals with results and discussions and the fifth chapter focus on conclusion and recommendations.

Chapter Two

2. Review of Related Literature

This section of the study looks in to review of articles and journals which are related to the issues under study, there are numerous studies that have been conducted regarding cerebral palsy including its diagnosis, symptoms, treatments and its effect on an individual and societal level. But main focus of this section is to emphasize on available literature that related to this study.

The researcher attempts to review the related literature, came across the literature that has much more stressed on the challenges that mothers of children with cerebral palsy in the rehabilitation have faced. The literature that focused on the role of mothers in the rehabilitation center to treat their children with cerebral palsy is rarely available. So the researcher mainly focused on those available literatures. There are some attempts of review by some researchers in relation to parental role for children with cerebral palsy in Ethiopia, which are too general and do not show the specific role of parents. Very few studies are related to exploring the role of mothers in rehabilitation center in treating children with cerebral palsy in rehabilitation center is the main focus of this study. .

2.1 Historical background of the of disability

Even if there is no exact agreement on the "definitions of disabilities", but there are little internationally comparable information on the incidence, distribution and trends of disability. According to world health organization, disability is "complexes, dynamic, and multidimensional" (WHO, 2011).

However, in Ethiopian contexts disability is defined as any person unable to ensure by himself or herself a normal life, because of deficiency in his or her physical or mental capabilities. NagaritGazeta of the Emperor Haile Selassie I, in the Order No. 70 of 1970, described the disabled as, people who is unable to earn his livelihood and do not have anyone to support him because of limitations of normal physical or mental health. In addition, shall include any persons who are unable to earn their livelihood because they are too young or too old.

In NegaritGazeta the Transitional Government of Ethiopia, Proclamation No. 101 of 1994 referred a disabled person as, a person who is unable to see, hear or speak or is suffering from mental retardation or from injuries that limit him or her due to natural or manmade causes. However, the term does not include persons who are alcoholic, drug addicts and those with psychological problems due to socially deviant behaviors. (JICA, 2002).

From all types of disability as the researcher mentioned before the main focus of this study was it's all about cerebral palsy. Cerebralpalsyis one of the most mutual developmental disabilities. A condition is started early in childhood and continuing throughout the lifetime. The definition and classification of cerebral palsy, according to the Executive Committee for the Definition of Cerebral Palsy, states that: "Cerebral palsy describes a group of permanent disorders of the development of movement and posture that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary musculoskeletal problems" (Rosenbaum et al. 2007).

2.2 Disability in Ethiopia

According to WHO, 10% of the population of any developing country is estimated to be people with disabilities estimate of ten percent (10%) is applied to indicate the scope of disability in Ethiopia, the figure will be as big as 17.6million(WHO,2011). But this figure has not been confirmed by the National Population and Housing Census conducted by the Central Statistics Authority (2007). Rather the census report designated that there were 864,218 PWDs of which 464,202 are Male and 400, 016 Female. Out of the total PWDs, 31.18% have leg, hand and body movement problems, 28.77% seeing problems and total blindness, 19.74% hearing and speech difficulties, 4.8% people with intellectual disabilities, 6.8% persons with mental problem and 8.78% with other disabilities. This data shows how much the issue of disabilities needs concern. But as the data shows person with cerebral palsy even they are not counted in their category as a one of independent disability types. For this reason the researcher desperately needs to thoroughly scrutinize the mothers' role of children with cerebral palsy.

2.3 Cerebral palsy historical perspective

"Historically, CP was predominantly studied in relation to the of the impairment. Discussion regarding the definition and classification of CP was first recorded in medical literature during the nineteenth century, predominately in French, German, and English language publications. However, what exactly the term 'cerebral palsy' describes has been debated for more than 150 years" (Morris 2007)

According to Morris, Cerebral Paralysis was associated with "musculoskeletal issues" "the seminal work describing cerebral paralysis, and particularly the related musculoskeletal issues, was elucidated by an English orthopedic surgeon named William Little in one of a series of lectures in 1843 entitled" (Morris 2007).

According to N. Havaei cited by (Dudgeon, 2001) Cerebral palsy is a developmental disability starting in early childhood. The cause is non-progressive damage of brain. Children with cerebral palsy have worldwide, “physical and mental impairments” and may have sometimes serious As a disability, cerebral palsy is one of the most mutualreasons for referral to occupational therapy (Dudgeon, 2001). Due to this disability, most people with cerebral palsy are limited in their activities. The motor disorders of cerebral palsy are often accompanied by disturbances. Among these disturbance are sensation, perception, cognition, communication, behavior; by epilepsy; and by secondary musculoskeletal problems. A person with cerebral palsy always faces life challenges due to their disability.

2.4 Classification of cerebral palsy

Cerebral palsy is a communal developmental disability first discovered by William little in the 1840s. “It is mainly a disorder of movement and posture”. It is explain as an “umbrella term “discovers a group of non-progressive common problem, the worldwide occurrence being 2 to 2.5 per 1000 live births. (Moniker 2005)

According to Gianluch and Vito, (2015) Cerebral palsy can be classified based on four major components: type and severity of the motor abnormalities, anatomical distribution, associated impairments, and timing of the presumed causal event.

Physical and neurological examination permits the identification of abnormal neuromuscular tone of hypertonic as well as the main type of motor impairment, which can be spastic, ataxic, dyskinesia or mixed. The characteristics and severity of the motor manifestations should be

defined for each limb and the trunk, thus differentiating unilateral from bilateral involvement and establishing an anatomical distribution (diplopia, hemiplegia, and tetraplegia).

According to, William.L (1840) cited by (C. Nandini (2005)Cerebral palsy is first described by the topographic classification of monoplegia, hemiplegic, diplegia and quadriplegia. Monoplegia and triplegia are relatively uncommon. There is a substantial overlap of the affected areas. In most studies, diplopia is the commonest form (30% – 40%),hemiplegia is (20% – 30%), and quadriplegia accounting for (10% – 15%).

2.5. Definition of Rehabilitation

According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 26, Rehabilitation is appropriate measures, including through peer support, "to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, full inclusion and participation in all aspects of life".

When we are thinking about disability and rehabilitation it is essential to remind that perceptions of disability are gradually changing. Since in the 1960s there has been a steady but increasing realization between legislators, policy makers and across the world that the difficulty ofdisability cannot be measurednormally individualistic medical terms (Barnes and Mercer, 2003)

According to, (Yirgashewa 2004) cited by Yeshimebet 2014 rehabilitation that offers service in the child with disability's create convenient environment effectively , and children who have access for actual and comprehensive rehabilitation can progress their movement and development. Simply they can be, self-regulating, emotionally well being and creative.

Rehabilitation services can be effective if it is intensive physical and sociological treatment.

In addition to this, (S. Ganesh Kumar, Gautam Roy, SitanshuSekharKarAlma Ata. 2012), declaration on 1978 specified that comprehensive primary health care should include promote, preventive, curative, and rehabilitative care.

Rehabilitation is a procedure of retrieval lost physical and mental functions. It is referring to "a process of regaining functionality from the physical and mental limitations or incapacitations of disability" (G.Fordiyee, 2006) cited by Mesfin2019.

2.6 Types of rehabilitation

Different types of rehabilitation service provision have been planned to offer appropriate device to person with disabilities and these can be classified three types of rehabilitation approaches, which is institution based, outreach based and community based rehabilitation approaches.

According to United Nations declaration on the constitutional rights of disabled persons (1975), underlines that "Persons with disabilities have the right to services such as human and legal rights". Rehabilitationhasto be measured equally a rights matter and not charitable trust to get rid of poverty and development of the nations. Nevertheless, the Convention on the Rights of the Child Untied Nation 1989 accepted that children's have right "to education and the right to rehabilitative services ensuring that children with disabilities have effective access to receive health, care services, education, training, preparation for employment, recreational opportunities and rehabilitation services" in this regard it is pivotal for children with disability to obtain rehabilitation Service as a human being and social integration.

2.7 Rehabilitation in Ethiopia

Permitting to, National plane of action of PWDs MOLSA (2012) the national level will have four main responsibilities. These are policy making, networking, human resource development and providing specialized services. This requires a strong coordination and collaboration among MOLSA, MOH and MOE. Thus, MOLSA as a lead Ministry will build up its institutional capacity by organizing a strong structure. Hence, the nucleus within MOLSA, the National Rehabilitation Centre of the Addis Ababa University Medical Faculty ministry of health and ministry of education will be fully responsible to carry out the above mentioned national level functions.

Multidisciplinary clinical team should be formed consisting of orthopedic surgeons, physicians, prosthetic-orthotics, physiotherapists, occupational therapists and social workers. It is to be noted that the clinical team will work under the supervision of someone who has a global knowledge of the rehabilitation process.

Affording to, National Plane of action Persons with disabilities2012, (NPAPWDs) presents a plane for enabling Ethiopia to become more inclusive society. It address the needs of people with disabilities in Ethiopia for compressive rehabilitation service, equal opportunities for education, skill training and work, and full participation in the life of their families, communities and the nation. It has been developed in consolation withkeygovernment ministers, UN organization, and people with disabilities and their organization, parents of children with disabilities and organization working on disabilities in Ethiopia.

2.8 Families of Children with Disabilities.

Families are the main source of support for children with disabilities. “Family members absorb the added demands on time, emotional resources, and financial resources” (Baker- Ericzen, Brook man-Frazee, &Stahmer, 2005)

The condition of successful support is a challenge, particularly mother of children living with Cerebral palsy and children with cerebral palsy involves suitable sustainable rehabilitation intervention which should efficiently meet to achieve of children and Caregivers/Family.

Families are one of the main supports of life-threatening for children with disabilities. “Family members absorb the added demands on time, emotional resources, and financial resources” (B.Ericzen, B.Frazee, &Stahmer, 2005). Non family members sometimes do not offer extensive care for children with disability as a family of children with disability. (Darling, 1987; Knoll, 1992)

2.8.1 Family-Centered Care

The starting from 1987 through Surgeon General Koop's request for "family-centered, community based care for children with special health care needs and their families," (Arango, 2011) The expansions of family centered care definition offered here spans at least twenty years.

In recent year underlineParental participation increasing in intervention programs is for childrenwith disability come across the special needsfor children living with disability. (S.K Campbell 1991, Kohn, 1990).Family-centered approach issupporting services for children with special needs.

2.8.2 Family/Mother involvement in the rehabilitation Center.

Resent research attention that family centered care has numerous contributions working to gather family and service provider to deliver the service. Rehabilitation including family focused treatment regimen as a model should be given attention for children with cerebral palsy deliver a team work. Rehabilitation of children living with CP is to involve parents in the rehabilitation center considering parent's opinions involvement in the rehabilitation ErdoganK.Filiz A. Ugur. Cavlak, A. Kavlak (2014).

The main goal of rehabilitation programs to reduce mobility problem and functional limitation is for cerebral palsy children. It consider as best experience to participate family of children the physical therapy for children with cerebral palsy is helpful at home exercise.

Mother of children with cerebral palsy involvement in the rehabilitation center is beneficial for compressive rehabilitation. It is the cause that more effective the adherence to home exercise stages in children with cerebral palsy; Professional has the same opinion plans concerning mother's involvement in the rehabilitation center. It has been profitable and speeds up the success of the goals of rehabilitation more improve mobility function for disabled children.

Basaranet.al (2013). Based on this, mother of children with cerebral palsy engagement in the rehabilitation center should be sustained medically and social integration to the successful home based treatment program.

They reinforce the "father- mother- child bond " interaction of physical therapist with family of children with disability is essential, as their joint work makes it possible to promote the acceptance of the treatment plan make easy and answering the question and treatment goals.

And it also intend to the importance of mother participation in the treatment program their role promote the overall activity to the sustainability provided that profit of the rehabilitationprocedureto go round raising family awareness physical therapy care at home, (A,

Carolina et.al 2016) To participate mother of children with cerebral palsy in the rehabilitation center is the most effective method and to acquire better performance result from rehabilitation center at home the physical therapy. Meanwhile, most research offered positive results had countless effect for family centered care for family of children with living cerebral palsy.

Family-centered role and care has become a cornerstone on rehabilitation services, a child – related with cerebral palsy are now commonly recognized on the source of the research. (King, Teplicky,& Rosenbaum, 2004). The primary aim of family role in physical treatment care is a long-term care is improving the child mobility problem and the family's quality of life, increasing the mothers' satisfaction with, and their involvement in, the rehabilitation program.

Chapter Three

3. Methodology

In this study explored the role of mothers of children with cp in the rehabilitation center. The Purpose of this study was to understand Mothers of Children involvement in order to sustain the rehabilitation services of the children beyond the center based rehabilitation services. Aqualitative interviews study was used in order to investigate the role of mothers, the perception of Mothers with CP and the challenge of mothers they faced at rehabilitation services, and to address the following research questions

1. What is the awareness/perception of Mother's about CP,
2. What are Mother's Valuable contributions and supports on the Provision rehabilitation services for their child's with CP
3. What challenges do mothers faced on services Provision at the center /at Rehabilitation center?

This study was situated in the interpretive paradigm and Primary concern is to understand the world as it is, at the level of subjective experiences of individuals.Interpretive analysis is holistic and contextual, rather than being reductionists and isolations. Interpretive tend to focus on language sign and meaning from the perspective of the participant involved in the social phenomenon, in contrast to statistical techniques that are employed heavily positiveresearch. Rigor in interpretive research is viewed in terms of systematic and transparent approach of data collection and analysis rather than statistical benchmark for construct validity or significant testing. (Susman, G.I. and Evered, R.D. (1978) Knowledge in interpretive Perspectives is constructed by individuals based on their interactions with, and the interpretations of the world around them. Accordingly, meaning exists in complex cultural, social, and institutional environments of individual experience (Clotty, 2003).Interpretive research assumes that

individuals create and associate their own subjective and inter subjective meanings as they interact with the world around them (Orlikowski & Baroudi, 1991, p.5).Thus, interpretive researchers attempt to understand the phenomena as it's from the meaning that participants assign to it.My duty as researcher in interpretive research was look at and understand situation as explained by my participant. In this study pool, interpretive perspective helped me to obtain and understand the awareness of mother about the mean cause their children disability, cerebral parsley (CP) ,mothers role and engagement in order to sustain and improve the rehabilitation services for their children ,And the challenge they faced at rehabilitation during service provision.

3.1. Research Approach and Design

This study employed descriptive qualitative research approach. The qualitative research approach helpsto the researcher to study nature of phenomenon by understanding the participants' point of view (De Vos, Strydom, Fouche, &Delpoort, 2011). The qualitative research design defined in various ways by different scholars. Strauss and Corbin (1988), defined qualitative research as a study design best to explore individuals' life, behaviors, emotions, feelings, lived experiences as well as cultural phenomenon, social movements and organizational functioning.

3.2. Research Setting: Cheshire Ethiopia (CE) and the Focus of the Research

Cheshire Ethiopia (CE) was established in 1962 by the grand Children of the late Emperor Haile Selassie and with technical support of CaptainLeonardoCheshire. CE is a local independent

NGO, staffed by Ethiopian and registered as an Ethiopian Resident Charity, with plying leading role in physical rehabilitation of persons with disability mainly children in Ethiopia.

3.2.1 Center Based Rehabilitation Program

The center based rehabilitation program is comprehensive pre and post-operative care along with physiotherapy, hydrotherapy, occupational therapy, donkey assisted therapy, handicraft training, informal and functional education, life skills training, counseling, mobility and walking appliances fitting and other therapeutic services enhance mobility and social functioning of children under rehabilitation.

3.2.2 Mobile Outreach Services

Historically the mobile outreach service was established to make follow up of children discharged from Menagesha Rehabilitation Center as rehabilitation services are unavailable in distant parts of the country. Currently the mobile outreach is deployed from three centers (Menagesha (22,) Hawassa (8), and Dire Dawa (8) making the total outreach post thirty eight.

3.2.3 Community Based Rehabilitation Program (CBR)

Community Based Rehabilitation (CBR) program is an off shoot of the mobile outreach services whereby children with developmental impairments such as mental retardation cerebral palsy and other multiple disabilities are rehabilitated using community approach.

Cheshire Ethiopia Reed House Pediatric rehabilitation Center

The rehabilitation Center has started its operation in October, 2010 and provides physical and electro therapy for children with developmental impairment especially cerebral palsy children

residing in the capital and it is closely working with different community based rehabilitationprograms through which referral linkages are established to admit the children at the center for rehabilitation service.

Cheshire Ethiopia Pediatric Rehabilitation Center which is found in Addis Ababa Yeka Sub City is my specific research area for this study where the researcher conducted the study.Pediatric rehabilitation center serve about 150 to 160 children per weekby rehabilitation worker, physiotherapy, Social worker, orto-prosthesis technologist and mother of children with CP regularly since these children need rehabilitation for certain period and mothers under go for training in the rehabilitation to acquire skills and knowledge to support and position their children with disabilities at home.

Sources of data

As it is an in-depth investigation the main sources of the data mothers who have children with cerebral palsy. These mothers are selected considering their children's age 5 and duration in the center in getting physical therapy treatment services,Technical manager of the center, social worker, Physiotherapy, Orto-prosthesis technologist and rehabilitation worker and documents of the center was source of Data.

3.3 Sampling and Sampling Techniques

To get data for this research, the researcher has selected respondent from mothers who came to the center in need of rehabilitation service for their children. From these simple random sampling techniques was implemented to get representative sample. To get representative sample from the services user of the center 40 parents were selected randomly. The selection was done on the services provision days of the center. From every client came to the center, mothers who

are willing to respond were selected. From the staff of the organization, those staff that has direct contact with the client was selected. From the staff selection 5 respondents who were rehabilitation worker 1 social worker, 2 of the respondents were physiotherapy and 2 respondents were Orto-prosthesis technologist, random sampling method was implemented.

3.4 Exclusive/Inclusive Criteria to Select the Participants

3.5.1. Exclusive criteria to select the participants

All Cheshire Ethiopia service provides center are not treated in all the country such as Menagesha, DireDawa ,Hawassa and Addis Ababa Rehabilitation centers. CE-Menagesha and CE-Dire Dawa admit 140 clients at a time, i.e. 120 and 20 respectively. Menagesha rehabilitation Center is a national rehabilitation and referral center for rehabilitation of Persons with disabilities mainly children aged 5-18 years affected due to post-polio paralysis. The children willing admits 70 clients at a time making the annual intake being over 140 children with the exception of those serious cases who stay more than a year despite of the average length of stay four to six months.

3.5.2. Inclusive criteria to select the participants

The study tried to treat the role of 40 mothers of with children cerebral palsy, and 9 experts at Reed House pediatric rehabilitation center. The study does not treat all the children with disability and do not consider all children with cerebral palsy of all Cheshire rehabilitation center in Ethiopia.It only Reed house Cheshire pediatricrehabilitation center.

3.5 Data Gathering Tools

For the collection data tolls two basic instruments were implemented. These basic instruments are questionnaires center document. The questionnaires were two types, one of the

questionnaires was for the mother of children with cerebral palsy who came to reed house rehabilitation center for their children rehabilitation service and the other is for service proving team of the center. The first parts of the questionnaires were the demographic part of the respondent. The second part is the questions about the role of mother in the rehabilitation center. The last part was question about the sustainability of physical treatment at home.

Based on all participants' preference interviews were conducted in the one of the conference room in the center. The interviews were recorded with the mothers' permission and lasted between 50 minutes to an hour and forty-five minutes. Interviews were also informal in nature and conversational to allow for open dialogue. Extra information, specifically about the life of mothers from FGD of rehabilitationworker who arerich in many years of experiences in giving physical treatment for children with cp were participating in the study also included

3.6 Method of Data Analysis

For this research the researcher select qualitative type of data analysis method. This method will give advantage of describing the situation in detail. The researcher believe that the qualitative method of data description of the situation give more clear picture of the problem for the readers. For these use percentage and frequency count of the information was compiled.

the experience of participants considering their culture, social environment and hypothesis weather their psychological frame work has been influenced by the world system or not whereas, phenomenology is concerned with explaining on how the participants understand a certain phenomenon and the way they understand themselves in the real world.

3.8 Ethical Considerations

These studies were acquiring agreement from ethical committee of Addis Ababa University, college of education and behavioral studies. Before data collection, permission of selected

rehabilitation center will be addressed through letters from Addis Ababa University. Self-introduction for rapport building and extending thanks for spending their precious time to participate in the study for each respondent. Principal investigator will explain the purpose and objective of the study to get informed respondent's consent to be voluntarily participate on the study. Concerned bodies were participated.

3.8.1 Informed Consent

The researcher clarified the aim of the research and gave the two participants with essential details. The consent paper given to participants and explained by the researcher to avoid any misunderstanding and encouraged asking any questions not clearly explained before signing the paper.

3.8.2 Confidentiality

As Burns (2000), stated that both participants and researcher must agree on the confidentiality of the information gathered from participant prior to interview. Hence, in this study, all participants were assured that any participant identifiers were kept confidentially and not discussing information obtained from interviews with others except for the researcher and the supervisor.

Chapter Four

4. Results

In the study 40 mothers' of children with CP, 9 Cheshire Ethiopia rehab workers conscripted. Through semi structured interview and focused group discussion the mother were to share their perception they had about the CP, the challenge they faced during provision of rehabilitation service for their children and the role they had on rehab services for their children even to sustain the basic rehabilitation services at home based level also. The organization managers and staff those hare closely engaged with rehabilitation services were explained and way forwarded about the role of mother in the rehabilitation services as well as the challenge of mothers they identified during services provision scenario during the semi structured interview. The findings of the qualitative interview study are presented in this chapter after analyzing the data obtained from interview and focused group discussion. Data analysis makes known that response incorporated around particular theme. These them were generated based on common response that parents gave to the interview question and focused group discussion.

4.1. Socio-Demographic Characteristics of Respondents

Socio - demographic characteristics of respondents which are included in this study were sex, age, marital status, educational background, employment status, from the field survey summarized as follows. The socio demographic characteristics 6 of managers were male and 25 of employees were male. In addition to this, 24 of the employees were female and 40 of mothers. 25 of mothers of children with cp children were in the age category of 41-50 years. Thus, the

majority of mothers were in the age category of 41-50 years. 27 of mothers were divorced, 24 of mothers of with cp children were secondary schools.

4.2. Theme 1. Perception (Opinion) of mother about CP

Studies were one of the essential part to explore how mother understand they have about Cerebral palsy (CP), Mother were asked to describe the initial concern about rehabilitation services. All mothers have different perception about the CP, the rehabilitation services and the development of their children with CP about the development of their children until the day they had diagnosed of CP. Thus I arranged these experiences in to the following sub theme:-Each participant was identified by the letter M (for mother) and numbered according to the sequence of the interviews

4.2.1 Sub theme 1: Community Belief & awareness about CP

Parents who have children with disabilities influenced by the Community belief and religion ideology most mothers seek solution for the cure of their children simply believing the community suggestion the case happened on their children is from evil and should be treated spiritual way . Most mothers tried this solution as a cure without having clear knowledge and awareness about Cerebral Palsy.

(M11)said "*I really obsessed that my child mobility problem have connected with spiritual matters and my neighbors' always told me to take him to spiritual place. And this belief long journey to get a solution since a get information about the therapy and rehabilitation services provided by Cheshire Ethiopia*

Some parents said that because of the Community belief and wrongly perception about CP made mothers to hide their children in the house without treatment for years afraid the cause of the disability since they heard about from community rehabilitation workers about disability and Rehabilitation services provided.

(M3)**, (M1), (M3),(M26) and (M40)**respondents said that "*we hide our children behind the world and locked our doors back believing that we are cursed because of our deeds with this case we didn't want show up our kids in public and kept them without getting any physical rehabilitation service with the reason of poor awareness we and the community had.*

Even though most of the mother of children with CP influenced by community belief and awareness some mother had clear in formation and awareness about CP and Rehabilitation however they claim the norm and belief community had about the disability.

(M9),(M10),(M28), and (M30) said that *"we had information and get diagnosed our kids since we have seen symptoms follow every needed procedure to help our kids but families , relatives and some community members tried to push them to took their kids to spiritual place for the cure rather than the rehabilitation services*".

The respondents said we pray to our God and we believe in him but we have to find also the option to make our children life better for their future like attending school and to engage their kids other community practices also.

During the focused group discussion also the participant shared their previous perception they had about the CP comparing with current understanding they have after their children started the rehabilitation services in Cheshire Ethiopia Reed house Rehabilitation Center. in the group

discussion **5(M31), (M32), (M33), (M34) and (M35**) mothers were attendedand they said "previously we had tried so many ways to get a cure for our children mobility problem but there is no solution beside the difficulties we faced with our kid at home but know our understanding and perception changed in way of what we can help our kids to enhance their mobility and their social participation with help of rehabilitation professionals together through the rehabilitation process.

4.2.2 Sub theme 2: The previous and current perception of Mother with CP about Rehabilitation services

Most mothers' participants in this study were unfamiliar with rehabilitation services. Some parents were also completely unaware of what rehabilitation mean and they never heard about it beside have enough understanding /awareness on basic rehabilitation.

(M11), told me during interview "*I never heard of it …. I was very surprised and feel hope when I heard the possible options for my kid mobility enhancement that so called rehabilitation from Cheshire Ethiopia community based rehab workers"*.

Other Mothers acquired limited information about rehabilitation even with higher education; the information held about rehabilitation was narrow, to some extent inaccurate or almost not existent.

(M10): *I thought Rehabilitation was provided for person who is in jail … and if you look up the definition it works for people who have a bad habit to change him to a good way.*

*(**M12**): It was not very fully known in our community we did not know too much about it even with my degree in Education department*

The lack of Mother's previous awareness about rehabilitation contributed to their struggle with understanding of the possible solution for their children with CP. All mothers described during interview and focused group discussion their initial emotion, interaction reaction and physical mobility of their children. Some mother reported feeling of depression, sickness and sadness when they think what to do about their kids in order to pave their daily activity life.

(**M23**): *My life totally changed I had severe depression, I was very sick, I was not like same what I used to be I became very sick and losing a hope on my kid's future*

(**M26**)*: I cried a lot, I was emotional, I was very sad while I think what to do the mobility issue of my kid with CP before I knew about rehabilitation services provision for case my kid had.*

When mother knew what rehabilitation mean and start confronting the initial feeling to their kid's situation they are able to better help their child as the Mother understand more about rehabilitation Versus CP the benefit for the child increase, as understanding often leads to early intervention. In this study mothers were asked their understanding about rehabilitation before and after their kid start rehabilitation services. Mothers response reflected their journey towards became informed, clarifying, that their understanding when they received information about rehabilitation. Mothers shared that they developed a better understanding and connection with their children through interacting with experienced center rehab workers and Physiotherapist. Their desire to help and support their child, which they know is an effort that will last their child entire life

4.3 Theme 2: The Role of Mother in the Rehabilitation

In my study I tried to explore the role of mother in the center while rehabilitation taken place in the center. During the focused group discussion and from case story observation the following findings were recorded. The rehabilitation center services for children with disabilities provided in different scenario beside adults at Cheshire Ethiopia reed house rehabilitation center. Through the process of rehabilitation services on kid spend weekly for a limited hour (about 2 up to 3 day) however the center use it maximum effort to change the limited mobility to enhancement. Through different rehabilitation approaches and modalities engaging mothers in the process of rehabilitation is mandatory as Center Physiotherapist said. On the Focused group discussion the participant said that "….without mother's full engagement nothing progress has shown because the kid came twice a week for therapy services staying 1 up to 3 hours with professional to get therapy but the rest of hours spent with parent specially with mothers thus center will gave a basic rehabilitation training skill for mothers how they can help their child at home." According to the participant way forward the basic rehab skill training will create great understanding about Cerebral palsy and the rehabilitation techniques to improve the physical mobility of the children on the daily activity of life and in order to sustain the rehabilitation services at home level. For example walking,speaking,bathing and performing any activity by his/her own. With this all scenario mothers will engaged themselves. For clear understanding I separately put the identified result through the following sub them:

4.3.1 Sub theme 1: Mother Role during rehabilitation Services

During interview the respondents replay on what can be the role of mother in the rehabilitation set up the respondents said "Present always with their kids during appointment, explain to the

physiotherapy if any new things show concerning with health status of the kids beyond that mother should applied at home which applied aims to improve the acquisition of functional skill by children with cerebral palsy (cp) to bring mobility improvement. Missing the Mother /parents will not bring change according to therapy plan"

The major role of mother during rehabilitation taken place also explained by the center physiotherapist during interview:

1. Mothers will facilitate early detection and diagnose if thathave seen and impairment and developmental delay for early treatment and management in order to avoid and complication affecting the child health in the future. Seeking early intervention is usually the best way to bring a solution based on the need and to establish rehabilitation treatment early intervention services include feeding support, identification of assistive technology that may help the child, occupational therapy& physical therapy.

2. Collaboration with center professionals, mothers should collaborate with professionals at all level of rehabilitation services provided in the center, a mother / parent can become an extra pair of hands for the therapist who can teach the intervention to the mothers to practice at home. Most importantly said the respondent, mother is accompanying the child for therapy that will reduce lots of problems of the child. Positive attitude of the mothers are very important in rehabilitation of their child

3. Active participation in therapeutic program; the respondent also explained the active participation of mother during rehab services because a child learns by touching, looking, listening and communicating. A mother can contribute a lot in early learning of the child. A

mother as parent should became an educator for the child throughout the rehabilitation process. In Addition to the rehabilitation set up the respondent explained the role of mother as follows: Addressing all aspect of child life is main thing because a child will not grow in terms of physical motor development only other aspect of child life, like interaction with peers, social and cultural involvement, education in the school and etc are very important. Most importantly mother can play an important role in mediating these aspects of child life

4.3.2 Sub theme 2: The role of mothers to sustain the rehabilitation services

In this study the researcher analysis and observed different case stories of children who have gotten rehabilitation services and I have got a chance to contact with the children and the mothers still those who have contact with the rehabilitation center serving other children and mothers as well. These mother have token the basic rehabilitation skill how to care and improve their child development. The explained the extended rehabilitation services in the community

Both the mothers **(M21)** and (M**29)** said *"we have completed the basic rehabilitation skill training while our kids getting therapeutic services in the center …. Then we have gotten basic skill and knowledge which enabled as to help our children as well to create awareness in the community about disability as well as the inclusive rehabilitation services"*

These mothers also said …. *It is our role to transfer skill and knowledge that gained from the rehab center to our community through mother to mother season, creating referral channel between community rehab workers and community mothers who have child with CP and other disabilities.*

Finally Most of the mothers answered during the interview appreciated the center inclusive rehabilitation services which engaged them to take a part and took responsibilities the home based rehabilitation services for their child which brings a tangible developmental improvement sustainable rehabilitation by exampling the stories of their child which I examined for data collection process.

4.4 Theme 3. Challenges of Mothers with Cerebral palsy in the rehabilitation services

In this study I tried to explore the main challenges they faced during rehabilitation service taken place in the center thus participant /mothers of Children with cerebral palsy explained the have been faced a lot of challenge with this case the following challenges were identified. The this study I used center staff and mothers of children with disabilities.

The participant / mothers of children with CP detailed explained the challenge they have been faced while they follow their children rehabilitation services in the center beyond the suspected stigmatization and possible depression they have been passed through out their life because of their child disability: Most of respondent explained the following challenge:

4.4.1Lack ofinformation:

All mothers pinned this issues the poor information about rehabilitation services in the community make them not bring their kids early to the rehabilitation. When they explained the lack of information they have the raised also the gap they identified information linkage with health facilities rehabilitation center.

4.4.2 Patient flow and services limited Capacity:

The respondent Cheshire Ethiopia Reed House rehabilitation center have limited capacity to serve the all client that referred to the center from all Addis Ababa Region and surrounding towns with this reason said the center staff , Mothers forced to wait more than a six month to start the rehabilitation process even at once. The respondent said the more on the waiting is the cause of limited capacity of the center.

4.4.3 Shortage of Assistive device

The center physiotherapist explained the shortage and lack of assistive device in the services provision. The professional said most children with CP need mobility aid devices like wheelchair and other devices which decrease the rehabilitation qualities through provision and create limitation on the children daily activity life.

4.4.4. Transportation Problem

Mothers said *"Because the disability type of our children had we suffered to get appropriate transportation while we came for the rehabilitation services"*

These challenges were identified only in the focus of rehabilitation services provision

5. Summary

The purpose of this study was to explore the role of mothers with children with cerebral palsy in the rehabilitation services the interview , focused group discussion and observation of children case stories used to identify the perception of mothers about cerebral palsy , the role of mother's in rehabilitation services and the challenge they faced during rehabilitation services.

After analyzing the data captured from interview, focused group discussion, case stories observation three main theme with subtheme linked form the date; Perception of Mother's about cerebral palsy , Role of mothers of children with cerebral palsy in the rehabilitation services and Challenges of mothers that faced during rehabilitation services when service take place.

These findings are most importantly assessed with research questions and matched with the research literature. In the next chapter also discussed, the researcher opinion, implication of the findings of center inclusive service and recommendation for the further study pointed

Chapter Five

Summary, Conclusion and recommendation

In this section the findings of the study are assessed in relation to the current research question, linked with the current relevant literature and the researcher explanation, implication of the findings for the center comprehensive rehabilitation services and way forward for future study are discussed in the chapter in detail.

5. Analysis of Current Study findings in relation with research questions

In this study explored the role of mothers of children with CP in the rehabilitation. The motto of this study was to understand significant role of mother of CP, perception of mother about CP and rehabilitation and the challenge they faced during rehabilitation services. As detailed figured out in the chapter 4 three major theme were identified regarding with rehabilitation services for CP children emerged from the data analysis.

1) The perception of mothers about Cerebral Palsy

2) Role of mothers in the Rehabilitation services

3) Challenges that mothers faced during the rehabilitation services.

In this scenario these findings are viewed in relation to current research question to link each findings to each research question to see how the research question were really addressed through qualitative research data collection method.

1st Research Question: What is the awareness/perception of Mother's about CP

A) How do community belief affect their understanding of their child with Cp versus Rehabilitation services

The first research questioned aimed to explore the perception of mothers about CP and also focused on how mothers understand their children's CP case , how the community belief and

understanding they have about the disability affect them , how the influence of community culture affect mother to decide what to as a mother of disabled child. During the interview mothers were asked to describe and reflect the initial perception about CP and the awareness they had about CP after their children start rehabilitation services with help of rehabilitation professional. Mothers separately discussed the influence of their community belief towards disability. For instance some mothers shared how community wrongly belief and practice affect them to perceive wrong ideas about CP thinking like they are a means of their child disability because of the deed (action) and cursed by God and their child is the result of the punishment. Additionally mothers discussed how this perception affect their children as well as the lack of knowledge about rehabilitation service also explained which is negatively affect their child development.

Further, Mothers reflect how emotionally affected when they spend their life with child with CP without having any tangible change because of the trail made to get cure for the disability of their children and lately knowing of about rehabilitation services provision and the consequence of behind explained during the interview.

In this study community perception about CP were discussed in order to reveal the influence that made mothers to understand about cerebral palsy as well as rehabilitation services. Not only was this issues discussed comparison of previous perception about versus current perception about CP and rehabilitation detail explained.

During the interview Mothers awareness about CP was completely different when they compared after they become a part of the rehabilitation process that given for their children at Cheshire Ethiopia Reed house Rehabilitation center.

These findings satisfactorily addressed the first research question as they clearly disclose Mother Perception about the CP. The perception was explained pre rehabilitation and post rehabilitation point of view.

2nd Research Question: What is the role of mothers of Children with CP in the Rehabilitation services?

The critical purpose of this study was to identify the role of mother's with CP in the rehabilitation process in the center. Mothers, Center Rehabilitation Professionals and Center managers were asked several question related to the role of mother's during rehabilitation. Additionally question raised for the participants the role of mother in order to sustain the rehabilitation services provision at community / home based level. These roles were identified during study: seeking early intervention, collaboration with center professional, active participation in therapeutic program and be mediator on social inclusion aspect of their child. Mother also expressed a variety of needs, which includes a willing to have more rehabilitation skill and information to assist in improving their child's abilities and mobility improvement and desire to share about disability and rehabilitation information to community mothers.

3rd Question: What are the challenges mothers faced during rehabilitation?

In this study mothers and center staff asked about the challenges and barriers that mothers faced in rehabilitation. The participant explained mother / parent challenge faced like lack or gap information towards disability and rehabilitation, limited capacity of the center to serve a more

clients at a time and Lack of transportation from home to center. The others respondent /rehabilitation professional / also disclosed the shortage assistive devices and physiotherapy equipment as a challenge to provide quality rehabilitation services.

These findings address the third research question. Further discussion of these findings is illustrated later in this chapter.

5.1Synthesis of current Study and previous research on related topics

5.1.1 Perception of Mothers about CP

Looking back different current studies Parents' perceptions about the nature of their children's disabilities have been a focal point among different cultural groups, including Mexican Americans, Chinese Americans, Africans, Turks, Iranians, Arabs, and Asians (Danseco, 1997; Daudji et al., 2011; Diken, 2006a; García, Pérez, & Ortiz, 2000; Kermanshahi et al., 2008; Masasa, Irwin-Carruthers, & Faure, 2005; Ryan & Smith, 1989). These studies have found that in every culture, disability is perceived differently. Moreover, these perceptions shaped parental attitudes toward their children with disabilities; the resources parents are willing to invest in the treatment, training, and education of these children; and parental expectations for the future of their children with disabilities. Parents from some cultural backgrounds have been found to hold dual biomedical and traditional beliefs regarding the nature, causation, and treatment of disability (Daudji et al., 2011; Diken, 2006b; Raman et al., 2010).

Historically, there has been a number of different definitions and understandings of disability, such as supernatural, spiritual and religious (Braathen, Munthali, &Grut, 2015; Goodley, 2011; Munsaka, 2012) with disability generally equated with incapability (World Health Organisation, 2011) and persons with disability as a burden to society (Khupe, 2010; Lang &Charowa, 2007).

One widely documented conceptualization of disability in African contexts is that a child born with a disability is seen as a curse, and should be hidden. One reason given for the curse is that the mother is punished for wrongdoing, and the child is living proof of her error (Curran &Runswick-Cole, 2013; Gona, Mung'ala-Odera, Newton, & Hartley, 2011; Marongwe& Mate, 2007; UNESCO, 2001). On the other hand, studies from African communities such as the Xhosa in South Africa (Mckenzie& Swartz, 2011), BaTswana in Botswana (Ingstad, 1997), In Zimbabwe, Dengu (1977) found that it was through the introduction of Christianity that disabled children started to be seen as gifts from God, although in some cases feelings of shame persisted, leading to cases of hiding.Muderedzi et al., Cogent Social Sciences (2017), Perceptions and beliefs about disability as a punishment, the result of ancestral anger or retribution by divine forces, have been found in many cultures (Braathen&Ingstad, 2006; Coleridge, 1993; Devlieger, 2005; Talle, 1995). A study from Ghana, (Wright, 1960) found that children with disabilities were seen as protected by supernatural forces, were the reincarnationof a deity and were always treated with kindness, gentleness and patience. Studies among the Shona and Kalanga of Zimbabwe, (Khupe, 2010; Lang &Charowa, 2007) have highlighted negative attitudes such as disabled people constitute a burden to society and that disability is associated with evil. A study by Jackson and Mupedziswa (1988) among the Karanga in Zimbabwe found that beliefs and attitudes expressed by informants toward persons with disability often seemed to be in contradiction with how they acted towards them.

Finding of this studies also indicate the same points mothers perceptions about the disability as well as Cerebral palsy shaped by community traditional belief which is wrongly interpreted towards the disability and the treatment with regards. In this study parent contribute late for rehabilitation treatment of their children because of the poor understanding and belief about their

children disabilities. These belief and perception drawn from the community attitude and understanding on the cause of some disability type like cerebral palsy.

Studies show that early diagnosis could lead to early intervention, which is crucial and associated with improved outcomes (Atun-Einy& Ben-Sasson, 2018; Dillenburger et al., 2016; Parents in this study attributed the delay in correct diagnosis to the rehabilitation reaction of ignorance to their concerns, which resulted in a delay in providing appropriate interventions and services to help their children. In this study parent expressed community awareness, maintaining linkage weredas and kebeles concerned body will create a good information communication line to have a good awareness and knowledge about disability and rehabilitation services.

Some of the mothers felt responsible for the condition of their child, like one of the mothers said, "I feel the herbalconcoction I collected affected the health of my child". Another mother responded, "I don't really understand why my child did not cry immediately, the only thing I can say is my child did not come out on time, and that prevented him from crying early". This statement is an indication that some of the mothers might have been well educated about the possible causes of the condition, as one of the mothers reported, "I was told he had jaundice and he did not cry on time which is what affected him". However, most of the mothers were optimistic in their beliefs about the improvement in attainment of developmental milestone by the child. Generally, the mothers of children with CP are often unaware of the cause of their children's ailments until they come in contact with health providers. Adequate education provided to the caregivers may produce positive belief among the caregivers

5.1.2 Role of Mothers of Children with CP in the rehabilitation center

Many studies focus on the role of the family in the long-term care of children with CP and consider the family part of a multi-inter-Trans disciplinary approach. Now a day, FCC/family centered care / is considered the best approach in CP rehabilitation. Devised by the Association for the Care of Children's Health, It focuses on the daily needs of children with CP, views parents as key resources for their children's lives, supports the idea that families and practitioners should collaborate within a child's rehabilitation program, that practitionersshould support parents in coping with their responsibilities, and that effective interventions by services and facilities must be based on the values, preferences, priorities, and needs of families. According to the FCC approach, the primary aim of long-term care is improving the child and the family's quality of life, increasing the parents' satisfaction with, and their involvement in the rehabilitation program, as they are the ones who know their child's needs and abilities better. Improving long-term care by putting the family at the center of this approach means recognizing their central role in the child's development and in the successful outcome of rehabilitation, as well as their knowledge of their child's needs. This shows how the family fits into multi-inter-trans disciplinary care delivery and collaborates with other stakeholders in the health care decision making*(*In this study also finding from interview, focused group discussion and case story observation revealed that the Most importantly said the respondent, mother is accompanying the child for therapy that will reduce lots of problems of the child. Positive attitude of the mothers are very important in rehabilitation of their child. A mother can contribute a lot in early learning of the child. A mother as parent should became an educator for the child throughout the rehabilitation process. In Addition to the rehabilitation set up the respondent explained the role of mother as follows: Addressing all aspect of child life is main thing because

a child will not grow in terms of physical motor development only other aspect of child life, like interaction with peers, social and cultural involvement, education in the school and etc are very important. Most importantly mother can play an important role in mediating these aspects of child life.

The need for empowerment stems from the inability of an individual or a group of people to achieve their ambitions and invest their full potentials because of the artificial barriers created by other individuals or groups within the same society; it's an expression of indisputable inequality, separation and marginalization.According to Oxfam 1995, "Empowerment involves challenging the forms of oppression which compel millions of people to play a role in their society on terms which are inequitable, or in ways which deny their human rights" Okeke submitted that "to empower means to give power to, to give authority to, to enable a person or a group of persons gain power". Batliwa (1995) in her definition of the term empowerment stated that: Empowerment is the process and the result of the process whereby the powerless or less powerful members of the society gain greater access and control over material and knowledge, resources, challenges and ideologies of discrimination and subordination and transform the institutions and structures through which unequal access and control over resources is sustained and perpetuated.The above mentioned dentitions show that empowerment implies that an individual or a group had previously lacked power or authority by circumstances, denial or default. The issue of women's empowerment has become a part of popular debate. It has however been misconstrued in a number of ways; to a great majority empowerment suggests women's power to fight men, including their husbands. But the intended meaning here is to empower women, especially mothers to play their roles in the family and society.(Basma journal , 2014)

Study show that tangible partnership with the mothers was built during the treatment process of their children that usually takes place for two to three weeks. The mother was trained to be the "in-house shadow therapist" for her child, the one who applies the exercises learnt following a specialized plan she is provided with once she returns back home. An evaluation to the child's condition is done after providing the mother with psycho-social support through individual counseling sessions.Increase the access to information and learning the best skills and practices during the mother's come to the center. Mothers observe and perceive the know-how transfer of the treatment done by the therapist during the first week of her stay, and then get involved in the treatment in the second week. Besides that, she takes a customized home program specialized for her child and starts performing the therapeutic exercises learnt. A follow up with the mother takes place after three months of the implementation of the home-program. Conducts field visits through the outreach program to approach the mothers and to ensure the continuation of the therapy with the mother and family. Is the psycho-social support program, where mothers are provided with psycho-social support services where individual and group counseling sessions take place Parenting skills might be a subject to be included in such sessions. The program includes releasing negative energy and emotions through ice-breaking activities and music therapy these approach according to the study result a remarkable rehabilitation services provided to children with CP as well as sustaining the rehabilitation services at home level by Mother's. (Basma, 2016,)

Mothers are typically responsible for all aspects of household management, such as cleaning and Cooking, as well as providing the majority of the day-to-day care giving for children (Ajrouchet al., 2016; Ajamiet al.2016). This was evident in the composition of the participants in this study (five mothers), which may be a reflection of these responsibilities, as mentioned above; I did not

intend to only interview mothers. Mother participants also reported that they were responsible for the daily care of their children, as well as being involved in their children's Education and interventions more than fathers were. The fact that mothers have the responsibility to provide the majority of the day-to-day care giving for children causes them a significant amount of stress. Mothers in this study expressed difficulty with having to care for more than one child and determining how to allocate their time and energy across all family members.

In the study also findings revealed that using ,mother as ambassador of the rehabilitation part more inclusive and result based and integration with the community based rehabilitation workers by training mother basic rehabilitation skill will create as knowledge transfer channel in the community in order to create awareness. This will create ownership among community members as well will create a sustainable rehabilitation services of children with cerebral palsy.

5.1.3 Challenge of mothers of children with CP faced during rehabilitation services

Several studies list the challenge of Mothers' with CP like the social problem they experienced, mother health problem ,financial problem experienced by mothers ,Pragmatic issue and social and emotional challenges.

But in this study the challenge were explored form participant focused rehabilitation services provision aspect. On this study the following challenges were explored from participant:

5.1.3.1 Information barriers / communication barriers

Communication barriers between health center staff and patients with disabilities are a big

Challenge. This is especially noted for people who have speech and hearing impairments (Gaihre et al. 2016; UPHLS 2015; Mprah 2013; Mulumba et al. 2014; Ganle et al. 2016; Ledger 2016; Tun et al. 2016; Kritzinger et al. 2014; Burke et al. 2017), and is expected to be similar for persons with intellectual or psychosocial impairments (but not proven as they were hardly included in any of the studies). Many healthcare providers at health facilities neither understand nor appropriately communicate in sign language, nor are sign language interpreters available to interpret (Gaihre et al. 2016; Ganle et al. 2016). For expectant women with disabilities, these same sources note that these barriers have resulted in life-threatening situations for both the mothers and unborn babies, with reports stating that deaf women have lost their babies because of their inability to understand the instructions of midwives. Other women experienced challenges inability to take patients medical history. Barriers are not only found in the direct communication between health care staff and patients, but also in the indirect communication, such as brochures and prevention or awareness campaigns. In this study also participant determined the communication and information gap between the services provider. During the focused group discussion participant disclose that mother were not fully aware about the rehabilitation service even if they tried to ask government health sector where can the treatment. Most mother were suffered to get full directive even where the rehabilitation center located this made them stay at home with their child without getting treatment for several years. During the focused group discussion also explained about the validity of some information that disclose for families /mothers of children with disability. This information was not valid and loses their reality because of the lack of channel staring from kebele, up to higher concerned bodies towards service user.

5.1.3, 2 Limited center rehabilitation services capacity

In this study findings show that there is high services demand. During my observation in the reed house rehabilitation center there were a lot of children with CP registered on the waiting list and most mothers also respond that by recalling their kids' admission process and duration date for admission they said it take long days more than three months. With this case mother will suffered on waiting long days in order to get services due to limited accommodation capacity at once in a session.

5.1.3.3Shortages of assistive device and physiotherapy equipment

The yearly publisher journal of BMJ innovation publication posted the research examine from 17 countries focused on Africa and Latin America countries they found that assistive device which range from wheelchair ,cane, prosthetic and orthotic devices , hearing devices are only available to about 1 in 10 people in the countries. in many low –income and middle income countries ,only 5-15% of people who require assistive devices and technologies have access to them (WHO , 2020 report) In this study also the identifies the shortage of assertive devise and physiotherapy equipment to provide for the children with cerebral palsy .

5. Conclusion

The result of the study revealed that creating information channel from the top to down which is used to as means awareness creation about disability and the possible way of rehabilitation treatment for person with disabilities especially for children who have cerebral founded mandatory in order to change the perception and belief about the cause of disability and the treatment.

The research also explored the vital role of mother in order to provide the full rehabilitation package in center based as well as community based rehabilitation services for children with cerebral palsy in way of change the daily life the children in school, at home and any social participation. In order to create a sustainable services provision the study explored that empowering women in aspect of knowledge transferring by providing basic rehabilitation skill to mother.

Mothers of children with cp need support from every mother of the society to raise their children. Children with cp have special need to be educated and socialize with their age meet. For these processes the children expect more socializing knowledge. mothers children with cp have different psychosocial problem like stress, emotional instability and hopelessness. In addition these mothers have social and family problem which need the intervention the general community.

Even if the center is doing good to rehabilitate persons with disability, the mother's condition is not under the program of the center. Rehabilitation is important for all persons in the world at one time of their life.

From the above analysis and result we can say that mothers of children with cp burdened by their children condition. Mothers are stressed, emotionally unstable, frustrated and confused with their child condition. The development of a country and it people have different aspects. One of the aspects is the awareness the people have about different diseases and situation in the community.mothers of children with cp do not clear understanding about their child disability and it rehabilitation.

As we can see from the above analysis, mothers of children with disability have different burden. More than half of the mothers need support from anybody. Mothers have great influence

on the family stability and the child future. Hence the contribution of government, non-government community and relatives of the family is enormous. More over the burden of mothers of children with cp need the contribution of different sectors like education service sectors, religious sectors, health services and other sectors too.

7. Recommendations

Based on the finding of the study the researcher attempted to recommends the following

- Most of the focus of the center is physical rehabilitation treatment. It is one of the rehabilitation processes that children with disability need. But without the provision of comprehensive rehabilitation service full rehabilitation will not be achieved. More over rehabilitation should also be given to the mothers and communities of the child. Hence the center should have to more plan rehabilitation treatment program for mother and communities.
- Mothers of children with cp need not only rehabilitation treatment for their children; rather the mother needs also rehabilitation in different forms. The center should have to work with different organization to support the mothers of children with disability Most of the parents do not have good understanding about their children disability condition hence the center in collaboration with government and non-government sectors support the mothers.

- The mothers of children with CP experienced challenges which affected them physically as well as emotionally and some of them experienced marital problems. Due to this the mothers were isolated and lacked social support and causing impact on the role they play to support children with cerebral palsy. Therefore, programs and policies need formulated and implemented to support mothers of children with disability particularly children with cerebral palsy. A family-centeredapproach strategies need to implement to managechildren with CP. This will decrease the challenges experienced and create conducive environment to mother to support children with CP.
- The center should have to give priority for the psychosocial rehabilitation aspect of the children well as the mothers of children with cp. Mothers of children with cp are found in stress and emotional challenge, more over there are mothers who have more than one child with disability. Hence the mothers need strong support to cope up with their children's condition
- Cheshire Ethiopia and other concerned bodies should Support for Parents of Children with Cerebral Palsy. Parents of children with cerebral palsy that requires ongoing support by making a*vailable resources, Care for Caregivers, Enhance Understanding* and *work together*. Both within the household and away from home, enlisting help from a spouse, counselor or support organization eases the pressure on primary caregivers or mothers.

REFERENCE

Aynuret al, (2013) Adherence to Home Exercise Program among Caregivers of Children with Cerebral Palsy

Aynuret al, (2013)

Ana Carolina Pereira Domenech, Keila Okuda Tavares, Aneline Maria Ruedell, Joseane Rodrigues da Silva Nobre (2016) Cerebral palsy: the meaning of physical therapy for mother caregiversDOI: http://dx.doi.org/10.1590/1980-5918.029.004.AO12*FisioterMov. 2016 Oct/Dec;29(4):757-65

Anjali, K G., Jose, T. T., Vasari, B. P., Nayak, A. K, Sayaitha&Yashodharan, R. (2017).Quality of life of mothers having intellectual disabled children.Maniplal Journal of Nursing and Health Sciences, 3(2), 67-72

Article 26, Habilitation and Rehabilitation, of the United Nations*Convention on the Rights of Persons with Disabilities* (CRPD).

Eulalia Hernandez, Elena M.Morron, Diego R. Ripoll, MerceBoixdos. (2013) Impact of Caring for a Child with Cerebral Palsy on the Quality of Life of Parents

Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Cambridge, MA: Harvard University Press.

Burden on Caregivers of Children with Cerebral Palsy: Predictors and Related Factors*(Rethlefsen, Ryan, & Kay 2010; Snider, Majnemer, &Darsaklis, 2010)

Blair.(2010); Bottcher(2010); adding et al. (2006).Burden on Caregivers of Children with Cerebral Palsy: Predictors and Related Factors*(It came the same topic)

Braathen, Munthali, &Grut, (2015); Goodley, 2011; Munsaka, (2012) Perceptions and treatment of children with cerebral palsy among the Tonga of Binga in Zimbabwe

(Brannen&Heflinger(2006) Pakula, Van Naarden Braun &Yeargin-Allsopp(2009).Challnges experience by mothers caring for Childern with CP in Zambia.

Borst,(2010)and Yilmazetal.2013 Challenges experienced by mothers caring for children with cerebral palsy in Zambia

Burns, R. B. (2000). *Introduction to research methods. London*: Sage.

Cerebral Palsy–Definition, Classification, Etiology and Early Diagnosis *Indian Journal of Pediatrics*, 72 (865-867)ChitraSankar and NandiniMundkur (2005)

Colin B,(2003) Scnadivian Journal of Disability Research 5 (1) 7-24:2003).

Crotty, (2003)Understanding research philosophies and approaches

(Danseco, 1997; Daudji et al., 2011; Diken, 2006a; García, Pérez, & Ortiz, 2000;Kermanshahi et al., 2008; Masasa, Irwin-Carruthers, & Faure, 2005; Ryan & Smith,1989).The Perception of Disability Among Mothers Living With a Child With Cerebral Palsy in Saudi Arabia.

Daudji et al,(2011) Diken (2006b) Raman et al, (2010)The Perception of Disability Among Mothers Living With a Child With Cerebral Palsy in Saudi Arabia

Davied Heseltine.(2001) Community Outreach Rehabilitation.

David and Susan L, Family of children with disability: A review of literature and recommendations for intervention. *Journal of Early and Intensive Behavior Intervention Page 93-94* volume 5 numbers 3

De Vos, A. S., Strydom, H., Fouche, C. B., &Delport, C. S. L. (2011).*Research at grass roots: For the social research and human services professions.* (4th ed.). Pretoria: Van Schaik

Disability and rehabilitation status review of disability issues and rehabilitation servicesin 29 African countries *disability and rehabilitation team who–geneva*2004.

Dunlap, Newton, Fox, Benito, & Vaughn, 2001; Fan & Chen, 2001; McConachie&Diggle.(2007).Mothers' Reports of Their Involvement in Early Intensive Behavioral Intervention.

ErdoganKavlak, FilizAltug, UgurCavlak, HavvaAylinKavlak (2014), Expectations from Rehabilitation of Children with Cerebral Palsy: The Agreement between the Physiotherapists and Mothers

Fulcher J and Scott J. (2007).*Sociology*.5th ed.New York and Oxford University Press.

Gianluch and Vito.(2015). Classification of cerebral palsy Orthopedic Management of Children with Cerebral Palsy *compressive approach.*

Gemma Louise Willingham-Storr, (2014) Parental experiences of caring for a child with intellectual disabilities Journal of Intellectual Disabilities 1–13

DOI: 10.1177/1744629514525132 jid.sagepub.com

Glasscoe et al. (2007); Sajedi et al. (2010).Challenges experienced by mothers caring for children with cerebral palsy in Zambia

HandeŞenol. (2014) Expectations from Rehabilitation of Children with Cerebral Palsy: The Agreement between the Physiotherapists and Mothers *J. Phys. Ther.Sci.Vol.*1210 *26, No. 8, 2014.*

Helander, E (2007) Theorigions of community based rehabilitation. (*Asia Pacific Disability RehabilitationJournal, 18(2) 1-7*

Hurley DS, Sukal-Moulton T, Gaebler-Spira D, Krosschell KJ, Pavone L, et al. (2015) International Journal of Physical Medicine & Rehabilitation 3(2) 1-13 doi:10.4172/2329-9096.1000266

https://www.cdc.gov./ncbddd/cp/data

http://cheshireethiopia.org

http://www.dinf.ne.jp/doc/english/asia/APDRJ/apdrj-vol18-2007-helan.htm.

Huss, Olsson, Andersson, Granlund, Augustin. (2017). Perceived needs among parents of children with a mild intellectual disability in Sweden

Japan International Cooperation Agency, 2002

Japan International Cooperation Agency, Country profile of Federal Democratic Republic of Ethiopia March 2002.

(Khupe, (2010); Lang &Charowa, (2007). Disability and development in Africa; poverty, politics and indigenous knowledge

Karen Wylie, Lindy,,BronwynDavidson, ,Julie Marshall,

Communication rehabilitation in sub-Saharan Africa: The role of speech and language therapists. African Journal of Disability ISSN: (Online) 2226-7220, (Print) 2223- 9170http://www.ajod.org

Klankadi, (2008) The experience of caring for child with cerebral palsy

MariolinKetelaar, AdriVeremmer, Paul J.M Heldens and Harm't Hart.(1998). Parental Participation in in Intervention programmers with children with cerebral palsy

TECSE 18:2 108-177 (1998) *Utrechat University.*

Max Van Mane. (1997) From Meaning to Method

Mesfin, (2019) Practices of intervention for holistic change on adolescents with disabilities behavior in two service provider agencies: Cheshire services and cure international

Michael Larkin,Simon Watts &Elizabeth Clifton .(2008). Giving voice and making sense in interpretative phenomenological analysis

Michelle L. Rogers. (2003)The Miriam Hospital l DENNIS P. HOGAN Brown University

Family Life with Children with Disabilities: The Key Role of Rehabilitation

Journal of Marriage and Family 65 (November 2003): 818–833

O. Victor, (2017) Distinguish between primary sources of data and secondary sources of data

Mabel Oti-Boadi, M. (2017) lived experience of mothers of children with intellectual disability in Ghana. Sage publication doi: 10.1177/215824017745578Mc Nally, A.,

Mohammed M Jan Annals of Saudi medicine · March 2006 DOI: 10.5144/0256-4947.2006.123 · Source: PubMed.

National Physical Rehabilitation Strategy Ministery of labour and social affairs (2011) http://www.molsa.gov.et

National plane of action Of PWDs (2012-2021)MOLSA (2012)

NagaritGazeta of the Emperor Haile Selassie I, in the Order No. 70 of 1970

Olawale, Deih&Yaadar.(2013).Yilmaz et al. (2013).Challenges experienced by mothers caring for children with cerebral palsy in Zambia

Orlikowski&Baroudi, (1991,p.5).Paradigmatic approaches used in enterprise resource planning systems research: A systematic literature review

Amy Thornhill Pakula,Kim Van Naarden Braun,MarshalynYeargin.(2009) Cerebral Palsy: Classification and EpidemiologyDOI: https://doi.org/10.1016/j.pmr.2009.06.001

Patton, M., Q. (2002).*Qualitative evaluation and research methods* (3rded.). Thousand Oaks, CA: Sage.

Pillow, W.(2003).Confession, catharsis, or cure? Rethinking the uses of reflectivity as methodological power in qualitative research.*Qualitative Studies in Education,* 16, 175-196

Polly Arango 2011 Family-Centered Care http://www .familyvoices.org

Volume 11, Number 2 :97-99

Rahel, W. (2014).Single mothers' experiences of raising their dependent children. Graduate school of social work. Addis Ababa University.

Resch et al. (2010).Depression Among Parents of Children With Disabilities

Robert W. (2012) Steep for Life.

Rosenbaum et al.(2007).The definition and classification of cerebral palsy.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, et al. (2007). A report: the definition and classification of cerebral palsy April 2006. Developmental Medicine and ChildNeurology, 109(Supplement), 8–14.

S. Goundar, (2012) Research Methodology and Research Method

S.Ganesh Kumar, Gautam Roy, SitanshuSekharKar. (2012) Disability and Rehabilitation Services in India: Issues and Challenges:http://www.jfmpc.co 1(1) 70-73,

Smith, J. A. & Osborn, M. (2003).*Interpretative phenomenological analysis.* In J.A. Smith, (ed.).*Qualitative psychology* .London: Sage.

Sanaa Mohamed Madi, Anne Mandy, and Kay Aranda.(2019) The Perception of Disability Among Mothers Living With a Child With Cerebral Palsy in Saudi Arabia.

Global Qualitative Nursing Research Volume 6:1–11The Author(s) 2019 DOI:10.1177/2333393619844096 journals. sagepub.com.

Smith & Osborn.(2003). Interpretative Phenomenological Analysis

Strauss, A., & Corbin, J. (1988).The basics of qualitative research: Techniques and procidures for developing grounded theory. (2nded.). Thousand oaks, CA: sage.

Streubert, H. J., & Carpenter, D. R. (2002). Qualitative research in nursing: Advancing the humanistic imperative (3rded). Philadelphia: Lippincott Williams &Wilkins.

Susan L. Neely-Barnes, Msw, PH.D. David A. Dia, MSW, Ph.D Journal of Early and Intensive Behavior Intervention VOLUME 5 - NUMBER 3 Families of Children with Disabilities:
A Review of Literature and Recommendations for Interventions.The University of Tennessee - Memphis Campus. (93-107)
The meaning of physical therapy for mother caregivers Fisioter.Mov., Curitiba, v. 29, n. 4, p. DOI: 757-765, Oct./Dec. 2016 Licenciado sob umaLicença Creative Commons

Tirusew, T (2005), Disability in Ethiopia: Issues, Insights and Implications. Addis Ababa University Printing Press, Addis Ababa.

Tirstwold A (2018), psychosocial and economic burden of parents of children with physical disability.

Tonga &Duger.(2008).Challenges experienced by mothers caring for children with cerebral palsy in Zambia

WegayehuTebeje (2004). A study of the principles and practices of community based
Vocational rehabilitation and its implication for Ethiopia, Ontario institute education. University of Toronto

Woldeab, C. T. (2006). Family, school, and community: Challenges in rising and educating children with intellectual disability: A case study among parents, teachers, and social workers in Ethiopia. Doctoral Dissertation. Oslo, Norway: University of Oslo, Faculty of Education.

Woldeab.C.T, (2007).Raising a child with Intellectual disability in Ethiopia. What do parents say?(Doctoral dissertation, Florida International University).Retrieved from.

World Health Organization.(2001).

World Health Organization. (2006)

World Health Organization. (2010)

World Health Organization (WHO 2011)

Appendix A

Semi Structured Interview Guide

1. What is your expectation (hope) that the rehabilitation center reduces your child mobility problem?

   Probes question/ideas

   - What kind of change your expectation?
   - In what condition you like to be your Child mobility?
   - What do wish your Child after the rehabilitation?

2. What are the main challenges (if any) the daily service provision?

   Probes question/ideas

Probes question/ideas

   - What is the challenge?
   - What is the accessibility challenge in service provision?
   - What are your Daily living activities?

3. What is your barrier to participate in the rehabilitation center ?

   Probes question/ideas

   - Is there any requirement challenge you to get the service in the center ?
   - What is the main problem to be a part of rehabilitation service that is given to the child?

4. What is your opinion the contribution of mother with CP child in the rehabilitation center bring a change?

   Probes question/ideas

   - What is in sustaining the rehabilitation at home?
   - What mechanism do you think that fasten their habilitation service to the cp child?
   - How prepared were you to care your child at home?

5. What was your feeling when the Medical Centers inform you that your child's have CP?

   Probes question/ideas

   - Do you have the information about cp before?
   - Have you seen a child with cp case before?
   - What was your reaction while you knew your child have cp ?

6. What is your role in the rehabilitations center?

   Probes question/ideas3

   - What do think your role during the rehabilitation service given to your child?
   - Do you think the rehabilitation service bring a change, If you participated?

7. What kind of difficulties do you face through Physiotherapy treatment your child at home?

   Probes question/ideas

   - What kind of rehabilitation treatment you give to your child at home?
   - Do you have a basic rehabilitation skill?

- What kind of difficulty do you encounter treat your child at home?

8. What is your opinion towards the service provided by the rehabilitation center?

Probes question/ideas

- What is your suggestion on center based rehabilitation service improvement?
- Do you have any opinion about inclusive rehabilitation service?

9. What is your difficulty to join in rehabilitation Center?

Probes question/ideas

10. Do you have any comment concerning to the center?

Appendix B

Demographic Information

Address _____

Marital Status _____

Level of Education _____

Employment Situation _____

Appendix C

Informed Consent Form for children with physical impairment (Amharic Version)

<u>የስምምነት ቅፅ በተሃድሶ በማእከሉ ዉስጥ አገልግሎት እያገኙ ካሉ አካል ጉዳተኛ ልጅ ላላቸው እናቶች</u>

ውድ የጥናቱ ተሳታፊ እንደምን አደሩ /እንደምን ዋሉ?

መስፍን እንዳለ እባላለሁ፡፡

በአዲስ አበባ ዩኒቨርስቲ የልዩ ትምህርት ፊላንት (የእስፔሻልኒድ) ትምህርት ክፍል የድህረ ምረቃ ፕሮግራም ተማሪ ስሆን ለሁለተኛ ዲግሪ መመረቂያ የሚሆን የማሚያ ጥናት በማድረግ ላይ እገኛለሁ፡፡ ጥናቱ በቼሻየር ኢትዮጵያ ተሀድሶ ማእከል ዉስጥ የተሃድሶ አገልግሎት እያገኙ ካሉ አካል ጉዳተኛ ልጆች ካሉዋቸው እናቶች ተሀድሶ ማእከሉ ለሚሠጠው የተሃድሶ አገልግሎት የእናቶችን ሚና የሚሠጠውን ጥቅም ትኩረት ያደረገ ነው፡፡

በመሆኑም ለጥናቱ ግብአት መረጃ መሰብሰብ ስለምፈልግ ላዘጋጀኋቸው ጥያቄዎች ተገቢ ምላሽ በመስጠት እንዲተባበሩኝ ፍቃደኝነትዎን በአክብሮት እጠይቃለሁ፡፡ በዚህ ጥናት ላይ የሚኖረው ተሳትፎ በፍቃደኝነት ላይ የተመሰረተ ሲሆን ምንም አይነት የገንዘብ ክፍያ አይኖረውም፡፡ ሆኖም ግን የእርስዎ ተሳትፎ በጥናቱ ላይ አብይ አስተዋፅኦ ይኖረዋል፡፡ ስለዚህ በጥናቱ ለመሳተፍ ፈቃደኛ ከሆኑ አመቺ ጊዜ ና ቦታ በመምረጥ ከ30 ደቂቃ በማይበልጥ ሰአት የድምፅ መቅጃ መሳሪያ በመጠቀም ለቃለ ምልልሱን እናደርጋለን፡፡ በጥናቱ ጊዜ የሚያካፍሉኝ ማንኛውም አይነት መረጃ ሚስጥራዊነቱ የተጠበቀ ከመሆኑ ባሻገር መመለስ ያልፈለጉትን ጥያቄ ያለመመለስ ፣ጥያቄ ና ማብራሪያ የማድረግ ፣ከጥናቱም እራስዎን የማግለል መብት ያለዎት መሆኑን እየገለፅኩ በተጠቀሱት ነጥቦች ዙሪያ የሚስማሙ ከሆነ ከዚህ በታች ስም ና ፊርማዎን በማኖር ስምምነትዎን እንዲገልፁልኝ በዚች ምልክት እንዲያደርጉልኝ(√) እጠይቃለሁ፡፡

የጥናቱ ተሳታፊ

ፊርማ----------

ቀን----------

ጥናቱን ያካሄደው

ፊርማ----------

ቀን----------

አካል ጉዳተኛ ልጅ ላላቸው እናቶች የሚቀርብ መሪ ጥያቄዎች

አድራሻ _____

የጋብቻ ሁኔታ _____

የትምህርት ደረጃ _____

የስራ ሁኔታ _____

አገልግሎት እያገኙ ካሉ አካል ጉዳተኛ ልጅላላቸው እናቶች የሚቀርብ ቃለ- መጠይቅ

1.በማዕከሉ የሚሰጠው የተሃድሶ አገልግሎት ለልጅዎን አካላዊ እንቅስቃሴ ለውጥ አምጥቶዋል ብለው ያምናሉ?

2.በማከዕሉ በሚሰጠው የተሃድሶ አገልግሎት የሚገጥሞት ችግር ምንድን ነው ?

3.በተሃድሶ አግልግሎት በተገቢው መንገድ ተሳታፊ እንይዳሆኑ የሚያደርጎት ችግር ምንድን ነው ?

4.በሚሰጠው ተሃድሶ አገልግሎት እናቶች ተሳታፊ እንዲሆኑ ምን አይነት አስተዋፅ አያደርጋሉ ?

5. የህክምና ባለሙያዎች ልጅዎ አካል ጉዳት እንዳለበት ሲነገርዎ ምን ተሰማዎ ?

6. በማዕከሉ የእስርዋ ሚና ምንድነው ?

7.በተሀድሶ ማዕከሉ የሚሰጠውን አግልግሎት በቤትዎ ውስጥ ለመስጠት የሚያጋጥምዎት ችግር ምንድን ነው ?

9 .የማዕከሉ አገልግሎት ለማግኘት ሲመጡ ምንም ችግር ይገጥሞታል ?

10. ማዕከሉ ስለሚሰጠው የተሃድሶ አገልግሎት ምን አይነት አስተያየት አልዎት ?

11. ተጨማሪ የሚሠጡት አስተያየት ካለ ?

አመሰግናለሁ!!!

Appendix D

Consent Form for Manager.

Good morning/Good afternoon

DearParticipant !

I am a postgraduate student at Addis Ababa University conducting a study for my thesis required as a partial fulfillment for the Master of degree in college of education and behavioral studies department of special need education. Therefore, I seek your cooperation in completing the attached research instrument tool designed to gather data for the study .The main purpose of the study is to identify the challenge faced by the role of mother in rehabilitation center to treat child with cerebral palsy.

You were selected as participant of this study and your genuine response is vital for the attachment of the study objectives.

I assure you that the information you give will be used only for research purposes and your response will remain confidential and anonymous. Your participation is completely voluntary and completion of this questioner denotes your informed consent to participate on this study.

So, if you are willing to participate in the study, please put the sign (√) on the space provided.

Yes, I do agree _____ No, I don't _____

Thank you!

Thanks on advance for your cooperation and genuine response!

I. Background Information

II. Sex

III. Address

IV. Material Statues

V. Educational back Gerund

VI. Employment Statues

Questioner for Manager.

1. What strategies and procedures are measured by the center to perform its activities?

2. What do you think the limitations/ weakness/ in service provision?

3. What is the strength of the center in the process of service provision?

4. What are the challenges of your rehabilitation Center?

5. How do these challenges can be addressed?

6. What is the main role of mother with cp child in your rehabilitation center?

7. Do you think your organization is changing the life of children with CP in the rehabilitation? No/ Yes how explain?

8. What kind of challenges do you face during the involvement of mother with CP Child in your rehabilitation Center?

9. What will have to be done in order to improve the service provision?

10. Is there national rehabilitation service manual? If your response is Yes, What is the main objective of this manual?

Appendix E

Consent Form for Supervisor, Section Head, SectionManager.

Good morning/Good afternoon

Dear Participant !

I am a postgraduate student at Addis Ababa University conducting a study for my thesis required as a partial fulfillment for the Master of degree in college of education and behavioral studies department of special need education. Therefore, I seek your cooperation in completing the attached research instrument tool designed to gather data for the study .The main purpose of the study is to identify the challenge faced by the role of mother in rehabilitation center to treat child with cerebral palsy.

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Yes, I do agree _____ No, I don't _____

Thank you!

Thanks on advance for your cooperation and genuine response!

I. Background Information

I. Sex _____

II. Address _____

III. Material Statues _____

IV. Educational back Gerund _____

V. Employment Statues _____

1. How do you observed the improvement of mobility problem the child with CP in the rehabilitation center?

2. What is your challenge in the rehabilitation center?

3. How do these challenges can be addressed?

4. How often you to encourage mother with CP child to engage in the rehabilitation Center?

5. How do you discourage mother with CP child to engage in the rehabilitation Center?

6. What is the main role mother with cp child in the rehabilitation center?

7. What is your opinion towards the service provided by the rehabilitation center?

8. What type of lesson or resources is available for mothers of children with CP home based Rehabilitation?

9. What kind of training is given in your rehabilitation Center for mothers of Children with CP to sustain in physical therapy?

10. Is there anything that you can add?

Appendix F

Consent Form for Focus group discussion.

Good morning/Good afternoon

Dear Participant !

I am a postgraduate student at Addis Ababa University conducting a study for my thesis required as a partial fulfillment for the Master of degree in college of education and behavioral studies department of special need education. Therefore, I seek your cooperation in completing the attached research instrument tool designed to gather data for the study .The main purpose of the study is to identify the challenge faced by the role of mother in rehabilitation center to treat child with cerebral palsy.

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Yes, I do agree _____ No, I don't _____

Thank you!

Thanks on advance for your cooperation and genuine response!

I. Background Information

I. Sex _____

II. Address _____

III. Material Statues _____

IV. Educational back Gerund _____

V. Employment Statues _____

VI. Questioner Focus group discussion.

1. How do you observed the improvement of mobility problem the child with CP in the rehabilitation center?

2. What is your challenge in the rehabilitation center?

3. How do these challenges can be addressed?

4. How often do you to encourage mother with CP child to engage in the rehabilitation Center?

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6. What is the main role mother with cp child in the rehabilitation center?

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8. What type of lesson or resources is available for mothers of children with CP home based Rehabilitation?

9. What kind of training is given in your rehabilitation Center for mothers of Children with CP to sustain in physical therapy?

10. Is there anything that you can add?

<u>አካል ጉዳተኛ ልጅ ላላቸው እናቶች የሚቀርብ መሪ ጥያቄዎች</u>

አድራሻ _____

የጋብቻ ሁኔታ _____

የትምህርት ደረጃ _____

የስራ ሁኔታ _____

<u>አገልግሎት እያገኙ ካሉ አካል ጉዳተኛ ልጅ ላላቸው እናቶች የሚቀርብ ቃለ- መጠይቅ</u>

1.በማዕከሉ የሚሰጠው የተሃድሶ አገልግሎት የልጅዎን አካላዊ እንቅስቃሴ ለውጥ አምጥቶዋል ብለው ያምናሉ?

2.በማከዕሉ በሚሰጠው የተሃድሶ አገልግሎት የሚጥሞት ችግር ምንድን ነው ?

3.በተሃድሶ አግልግሎት በተገቢው መንገድ ተሳታፊ እንይዳሆኑ የሚያደርጎት ችግር ምንድን ነው ?

4.በሚሰጠው ተሃድሶ አገልግሎት እናቶች ተሳታፊ እንዲሆኑ ምን አይነት አስተዋፅኦ አያደርጋሉ ?

5. የህክምና ባለሙያዎች ልጆዎ አካል ጉዳት እንዳለበት ሲነገርዎ ምን ተሰማዎ ?

6. በማዕከሉ የእስርዎሚና ምንድ ነው ?

7.በተሀድሶ ማዕከሉ የሚሰጠውን አግልግሎት በቤትዎ ውስጥ ለመስጠት የሚያጋጥምዎት ችግር ምንድን ነው ?

9 .የማዕከሉ አገልግሎት ለማግኘት ሲመጡ ምንም ችግር ይገጥሞታል ?

10. ማዕከሉ ስለሚሰጠው የተሃድሶ አገልግሎት ምን አይነት አስተያየት አልዎት ?

11. ተጨማሪ የሚሠጡት አስተያየት ካለ ?

አመሰግናለሁ!!!

Appendix D

Consent Form for Manager.

Good morning/Good afternoon

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So, if you are willing to participate in the study, please put the sign (√) on the space provided.

Yes, I do agree _____ No, I don't _____

Thank you!

Thanks on advance for your cooperation and genuine response!

VII. Background Information

VIII. Sex

IX. Address

X. Material Statues

XI. Educational back Gerund

XII. Employment Statues

Questioner for Manager.

1. What strategies and procedures are measured by the center to perform its activities?

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Appendix E

Consent Form for Supervisor, Section Head, Section Manager.

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Yes, I do agree _____ No, I don't _____

Thank you!

Thanks on advance for your cooperation and genuine response!

I. Background Information

VI. Sex _____

VII. Address _____

VIII. Material Statues _____

IX. Educational back Gerund _____

X. Employment Statues _____

1. How do you observed the improvement of mobility problem the child with CP in the rehabilitation center?

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10. Is there anything that you can add?

Appendix F

Consent Form for Focus group discussion.

Good morning/Good afternoon

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Yes, I do agree _____ No, I don't _____

Thank you!

Thanks on advance for your cooperation and genuine response!

I. Background Information

VII. Sex _____

VIII. Address _____

IX. Material Statues _____

X. Educational back Gerund _____

XI. Employment Statues _____

XII. Questioner Focus group discussion.

1. How do you observed the improvement of mobility problem the child with CP in the rehabilitation center?

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8. What type of lesson or resources is available for mothers of children with CP home based Rehabilitation?

9. What kind of training is given in your rehabilitation Center for mothers of Children with CP to sustain in physical therapy?

10. Is there anything that you can add?

Declaration

I, the undersigned, hereby declare that this research report is my own work. It is being submitted for the degree of Masters of Special Needs Education at Addis Ababa University. It has not been submitted for any other degree or examination at this or any other university. All sources of materials used for this thesis have been duly acknowledged.

Name: Mesfin Endale

Signature: _____

Date: _____

Place: _____

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