

Addis Ababa University

College of Education and Behavioral Studies

Department of Special Needs Education

Psychosocial Challenges Encountered By Mothers Having Children with Cerebral Palsy at Cheshire Service Ethiopia, Addis Ababa

By: Oumer Seid

JUNE, 2020

ADDIS ABABA, ETHIOPIA

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This Thesis is submitted to the Department of Special Needs Education in Partial Fulfillment of the Requirements for Master of Arts Degree in Special Needs Education

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Declaration

I (Oumer Seid) declare that, this thesis hereby submitted by me is entirely my own original work except those sources which are obviously acknowledged. In addition to this, I declare that, this study has not been submitted and presented in anywhere else other higher learning institution for the award of any academic official documents.

Researcher's name: **Oumer Seid**

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This is to declare that, the thesis entitled "Psychosocial Challenges Encountered by Mothers Having Children with Cerebral Palsy at Cheshire Service Ethiopia, Addis Ababa." is done under my close supervision.

I recommended that, it could be submitted for the fulfillments and requirement of MA degree.

Tilahun Achaw (PhD.)

Advisor's Name_____

Signature_____

Date_____

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Acronyms

BCTE	Bonga College of Teacher Education
CP	Cerebral Palsy
CSE	Cheshire Service Ethiopia
FGD	Focus Group Discussion
GO	Governmental Organization
MTU	Mizan Teppi University
NGO	Nongovernmental Organization
UNDP	United Nations Development Program
W.H.O	World Health Organization

ABSTRACT

Cerebral palsy (CP) is a permanent neurological impairment that caused by a damage of central nervous system that present before or during birth or in the first month of life & mainly characterized by non-progressive, abnormal motor control, unusual and non-standardized posture with communication difficulties. The consequences of CP do not affect only the child's life but also the families. However, mainly the professional care has mainly focused and provided merely from a child's perspective and mother side is less concerned. *The objective of the present study was to explore the psychosocial challenges encountered by mothers having children with cerebral palsy in Addis Ababa, at Cheshire Service Ethiopia. The study employed a qualitative approach with a phenomenological research design. To find out pertinent response, the researcher recruited thirteen biological mothers of children with CP and selected them using purposive sampling method. From the total of thirteen respondents, seven of them participated in individual face to face interview and the remaining six participated in focus group discussion (FGD). The data was collected through semi-structured interview and FGD. Then analyzed qualitatively, using thematic analysis approach. From the findings of the study the following conclusion are drown. Before the birth of their children with CP there is lack of accurate information in regards to the concept of CP. The burden of care giving demands makes the mothers to be shocked and overwhelmed. These consequences, make mothers to faced psychological distress, social isolation, financial and marital problem, physical health problem (particularly, shoulder and back pain problem), lose of work opportunities and become unemployed. One of the cause of psychological challenges is discrimination that made by the community. There is a healthy mother-children relationship & have immediate eye contact even they are on the work because of their fearfulness may their children acquire further impairment. The most common coping mechanisms that employed by respondent mothers are, accepting their children's disability, regulating once emotion, religious coping, and receiving social support. The researcher recommended that, the government should access developmental physiotherapy services in the country. The societies must build up a positive perception towards mothers of children with CP. the physical, educational & the attitudinal barrier that existed in school could be adapted.*

Key words: Cerebral palsy, psychosocial challenge, mothers and children

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CHAPTER ONE

INTRODUCTION

1.1.Background of the Study

Cerebral palsy (CP) is a non-progressive disability present from birth or infancy that includes various neurological patterns of dysfunction and characterized by abnormal motor control, unusual and non-standardized posture with communication difficulties (Turk, Scandale, Rosenbaum & Weber, 2001; Wichers, van der Schouw, Moons, Stam, & van Niewenhuizen, 2001). Cerebral palsy has an effect on the child's activity, body movement and posture (Becker & Yalcin, 2010). In the word the incidence of CP has been estimated to be 2 to 2.5 per 1,000 live births (Reddihough & Collins, 2003). As confirmed by (Brannen & Heflinger, 2006), CP is the commonest cause of neurological impairment in childhood and is associated with lifelong disability. CP is the most common cause of physical disability in childhood worldwide but little is reported on the condition in the African context (Dambi, Jelsma & Mlambo, 2015).

Most of the time, children with CP are unable to do their day to day living activities effectively as other typical children, due to this, always they require their parents to assist them to meet around for their needs. As confirmed by Heward (2006) as cited in Kholoud (2013), CP can lead to limit a child's ability to perform his/her daily living activities such as eating, dressing, toileting and bathing and trouble to engage in age-appropriate social groups. Due to multiple impairments, some children with CP are absolutely dependent on others to obtain assistance for daily living activities (Resch et al, 2010). In fact, such limitations occurred on the children's life have enormous impact and influence the life of parents. According to Raina et al., (2005), CP is a chronic condition that may have serious consequences not only for a child's life but also for the family**.**

Previously a number of researches are conducted on the issues of psychosocial challenges experienced by mothers of children with CP in developing countries. For instance, Steadman (2015); Mukushi (2018); Desiko (2017); Singogo (2012); Dambi, Chivambo, Chiwaridzo, Matare (2015); Michael1 (2019); Olawale, Olajide, Abraham and Rphael (2013). The result revealed that, mothers are faced greater amount of psychosocial challenges that resulted from the

lifelong care giving demands, lack of financial assistance, misconception that made by the society, worrying for the child's autonomous life and others.

Mothers regularly experience various challenges on their psychological as well as social wellbeing (Rosenbau, Brehaut, Walter, Russell, Swinton, Zhu & Wood, 2005; Moster et al., 2010). Parents of children with CP have higher levels of psychosocial challenges compared with parents of children without disability (e.g. Barlow, Cullen, & Cheshire, 2006). Mainly mothers of children with CP have been experience psychological problems (Vijesh & Sukumaran, 2007). Due to having children with CP, usually the family units of such children felt constant worry by considering the children's life. Earlier studies confirmed that, Parents of children with CP often experience higher levels of stress because of their worries for the child's future (Ong, Afifah, and Lve, 2008**;** Parkes et al., 2011). Parents of children with developmental disabilities, including CP, experience greater parental stress (Gupta, 2007; Cheshire, Barlow, and Powell, 2010).

The lifelong responsibilities of caring such children with CP trouble the life of the parents as a whole particularly, difficult for mothers. According to (Davis et al., 2009), caring children with CP affects all facets of parents life including physical wellbeing, social well-being, freedom and independence (i.e. limited freedom), family well-being (i.e. pressure on marital relationships), financial stability and support of services. Actually, the care taking responsibility is the ordinary tasks for parent but these tasks are completely different, if the child experiences functional, sensory and intellectual limitations which create probably a lifelong dependence with their families (Tonga & Duger, 2008). Caring children with a disability impacts on many aspects of the parent's life, including, physical, social and emotional well-being, marital relationships, and employment and financial constraints (Blacher & Bromley 1990; Raina et al. 2005).

CP can have an effect on a child's ability to produce clear signals that are consistent over time. Children with CP seldom motivate for exchanges in spoken communication with their parents. For mothers of children with a disability it is difficult to understanding some of their child's cues Bailey & Simeonsson (1988). Mothers who are unable to obtain some guiding cues or feedback from their child may experience further stress and which limits their interaction (Fewell, 1986).

In order to make the demanding conditions to be more manageable, mothers of children with CP employed several coping mechanisms to adapt and deal with stressful situation. But mainly mothers of children with CP were challenged to cop their stress easily. Coping by itself is

positive or negative. According to (Pottie, Cohen, and Ingram, 2008), social support, positive reframing, emotional regulation, and religious coping are positive adaptive coping; while self guilt, blaming oneself, withdrawal from the social groups, and crying coping styles are decrease the daily positive feeling and associated with negative way of coping. According to Croot et al., (2012), as cited in Diseko (2017), described that, acceptance of the child, faith and social support is considered helpful for mothers in managing the challenge of raising a child with disability. According to (Tirusew, 2005), accepting and tolerating personal limitations by oneself, being strength in religious or praying are the major elements for unfolding and strengthening resilience. Some of a common coping strategy that employed by mothers of children with CP are accepting the child's disability, religious coping, regulating once emotion and receiving social support from community members.

As the report of world health organization, mainly a number of studies were conducted in developed countries as regards to mothers' experiences of care giving demands, but that have been investigated in developing countries including low and middle-income countries are less concerned (Thrush & Hyder, 2014; W.H.O, 2011). According to Resch et al., (2010), it is important to explore and understand in terms of parental experiences in caring children with disability. However, it is significant to carry out in a primary caregiver's (mother's) perspective in terms of psychological and social challenge. To the best knowledge of the researcher's review, this kind of research has never been conducted in Ethiopia because there is no available published and unpublished literature in Ethiopia regarding to the current issue. These all are prompted the researcher to undertake the present study Therefore, the aim of the present study was to address the psychosocial challenges encountered by mothers having children with cerebral palsy in Addis Ababa, at Cheshire Service Ethiopia.

1.2. Statement of the problem

For most parents, the birth of their children is a unique and touching moment. During pregnancy, parents especially, mothers generally build up and have an optimistic expectations of how their child will become and how they will be as parents (Leerkes & Burney, 2007). Most mothers are extremely upset when their child is identify with neurological disorder for instance CP, epilepsy, intellectual disability, autism and others; mainly because of the stigma and extra parental burden associated with such disorders.

In indifferent countries of the world, several studies were conducted on the issues of psychosocial challenges experienced by mothers of children with cerebral palsy. For instance, In one qualitative study, which was carried out by Nimbalkar, Raithatha, Shah, and Panchal (2013), on psychosocial problems among parents of children with CP and its finding revealed that, mothers experienced disturbed social relationships, health problems, economic problems, unhappiness, worries about the future of the child, need for more support services, and lack of adequate number of trained physiotherapists.

In Zimbabwe, Mukushi (2018), also conducted on psycho-social challenges faced by caregivers of children with cerebral palsy and the result demonstrated that, the major challenge of caregivers of children with cerebral palsy are facing discrimination, caregivers have no enough capacity to care for their children, frustrated to meet the financial and physical needs of their children. Similarly, earlier study carried out by Singogo, (2012), on the challenges experienced by mothers of children with CP and the result demonstrated that, mothers of children with CP experience psychological, physical health, socio-economic, environmental and marital challenges.

The research findings on psychosocial problem faced by parents of children with neurological disorder conducted by Nyasor (2012), the result indicated that; parents are unable to accept the long-term nature of the disability and so feel hopelessness. As the result of one co-relational study that investigated by Pugin (2007), on the issue of, the relationship between severity of CP in children and the levels of stress experienced by their parents and the result revealed that, parenting stress is complex and that is not a simple matter to predict the parenting stress levels of caregivers of children with disability.

According to Karumuna and Mgone (1990), on the parents' angle there are limited and few studies were investigated in low and middle income African countries. Likewise, in Ethiopia, the psychosocial challenges experienced by mothers of such children are seldom studied. Due to the knowledge of the researcher's review in our country Ethiopia, the literature as well as the professional care has focused mainly on the needs and developmental aspects of disability from a child's perspective but mainly studies focusing on the consequences of CP towards the child's mother side is less concerned. For instance, in particular, for such children with CP the

intervention process were concerned for the child, like providing physiotherapy service. Studying on the mothers' psychosocial wellbeing are the most disregarded issue and do not take into account by concerned professionals. In addition to this, limited understanding and inattention is obviously observed among physiotherapist, health care professionals and even with practitioner. But mother's psychosocial well-being plays a vital role for the whole developments of the child. Those all are the main gaps that noticeably observed in the prior research and could be addressed by the present study. Hence, it is necessary to find out the psychosocial challenges faced by mothers of children with CP in developing country, like Ethiopia. Therefore, this study will be gain insight and fill the gaps that into the psychosocial challenges encountered by mother having children with CP in Addis Ababa, at Cheshire service Ethiopia.

1.3. Objective of the study

The general objective of this study was to explore the psychosocial challenges encountered by mothers having children with cerebral palsy in Addis Ababa, at Cheshire service Ethiopia.

1.4. Research questions

In accordance with the aim of the study, the research is designed to find out answers for the following research questions

1. What are the psychological challenges faced by mothers of children with CP?
2. What are the care giving challenges that faced by mothers of children with CP?
3. What look like the mothers interpersonal relationship with their children with CP?
4. What are the possible coping mechanisms employed by mothers of children with CP?

1.5. Significance of the study

Studying on the issue of psychosocial challenges encountered by mothers having children with CP has several benefits. As stated by (Raina et al, 2005), addressing the psychosocial challenges experienced by mothers of children with CP enhances the quality of life for the child and keep as well as to enhance the mother's social and psychological well-being. For instance, mothers develop a potential to cope and deal with stress in regards to take care of their responsibilities towards caring their children with CP, Increase mothers social interaction and the societies to build up a positive insight towards mothers of children with CP and their children. Mothers of

newly screened children with CP get an opportunity to learn from others how to cope and deal with stress in regards to take care of their responsibilities towards caring their children with CP. . it serve as reference for concerned professionals, policy maker, program developer and organization those worked with children with CP to successfully implement their vision and mission through filling their gaps and to give more consideration for strengthening the mothers' psychosocial wellbeing. In fact this research could be stepping stone for other researchers who want to conduct research on the same area since; to the best knowledge of the researcher's reviews, no more studies have been revealed the finding in line with the current study.

1.6. Scope of the study

It is better when this study is conducted throughout the country for all mothers of children with CP. However, due to different constraints, the present study is geographically limited in Addis Ababa, at Cheshire service Ethiopia. Accordingly, in this study biological mothers of children with CP who are at the present time their children's with CP are attending developmental physiotherapy service at Cheshire service Ethiopia are focused. Because of the large number of children with Cp and their mother's are found in the study area to receive developmental physiotherapy service. Furthermore, it is better to have easy access to get sufficient data in regards to the current issue. On the other hand, conceptually this study was delimited only to the psychosocial challenges encountered by mothers having children with cerebral palsy.

1.7. Definition of key terms

Cerebral palsy- is known as a disorder of the central nervous system and it constitute permanent, non-progressive anatomical damage of the motor centers of the brain which manifests impairments in both mobility and posture. It has also been defined as a permanent impairment of muscle tone and movement which is caused by a damage of the evolving nervous system before or during birth or in the first months of life (Rosenbaum et al., 2006).

Psychosocial challenge- for the present study, psychosocial challenge represents the problem of both psychological and social aspects of mothers towards having and caring children with CP. In the other word, the social aspect that restrict mothers interaction as regards to having children with CP and the emotional state that affect the mother's life are psychosocial challenge.

Coping mechanisms - for the purpose of the present study, coping mechanisms refers to a strategies that employed by mothers of children with CP to adapt, manage and regulate stressful situation to maintain their emotional well-being towards caring their children with CP or a mechanisms which are parents used to deal with challenging or stressful situation emanating from having a child with CP. A strategy which seeks solutions to stressful situations or problems that emerges because of our stressors to have psychological comfort (Lazarus and Folkman, 1984).

Mothers- for the present study, mothers represent biological mothers and a primary care taker of children with CP and in this study the term mother and caregiver will be used interchangeably. Mothers refer to a primary care taker of the child who are directly responsible for the well-being of the child in decision making on a day-to-day basis and who may or may not be their biological offspring (Merriam Webster dictionary, 2010).

CHAPTER TWO
REVIEW OF RELATED LITERATURE

2.1. Definition and basic concepts of cerebral palsy

In the early years realizing the correct and acceptable concept of CP among the society has always been a challenge and numerous attempts have been made. In 2007, taking into account its complexity, the following concept was repeatedly expressed, CP described as a group of permanent developmental disability of movement and posture, restricted an individual's activity, that are attributed to non-progressive disorder which occurred in the developing fetal or infant brain. Mainly the motor as well as the physical disorders of CP is come with the disturbances in communication clarity, perception, sensation, cognition, and behavior problems (Rosenbaum et al., 2007). CP is one of a common developmental disability that initially made the following concepts earlier, CP is one of the three most common lifelong developmental disabilities, the remaining two are; autism and intellectual disability which causes greater pain that affected both individuals and their families. CP is one of incurable disorder that causes problem of movement and balance. It is caused by brain injury or mal-development of the developing brain resulting in physical disability in varying degrees.

2.2. Psychological challenges experienced by mothers of children with CP.

Mother's psychological wellbeing plays a vital role in the quality of care delivery and positive outcome for whole development of the child. Parents of children with CP are facing several social challenges and emotional burden further than the typical parenting experience which can place them at risk of poor psychosocial well-being. For example, as clearly confirmed by earlier researchers listed bellow, parents of children with CP have higher levels of psychosocial challenges compared with parents of children without disability and population norms (e.g. Barlow, Cullen, & Cheshire, 2006).

In this section the sub heading that included are mothers' initial reaction, perceived sign of depression and stress, and source of depression and stress.

2.2.1. Mothers' Initial reaction

In most cases, almost all mothers of children with CP expected to birth and obtain a healthy child. However, after knowing their children born with CP, they become worried and trouble to

accept the realities. Shocking is usually one of the first reactions and usual due to unexpected results of their children's diagnosis. As described by Ozsenol et al, (2003), mainly mothers are explained their state of being of shocking is through crying, unresponsiveness/silent and feeling of helplessness. In some instance, even after hearing the diagnostic result, they assumed as a health problem and cured or returned to a normal condition; this is because of less awareness for the facts in regards to CP. Mainly mothers are unable to accept the diagnostic results of their children and they lost hope of being a parent Huang, Killett & John (2010); Whittingham et al., (2013).

If a child is screened out as having CP, being of grief and worry are a normal reaction for most mothers of such children. Studies have revealed that according to (Huang, Killett & John, 2010) as cited in (Singog 2012), the first reactions of mothers are varied among mothers, but almost they experience periods of fearfulness, anxiety, panic, frequently face overwhelming depression, complete lack of regulating personal emotion and bitterness is common.

In some instances, a parent especially mothers are felt in their minds as regards to the considerable potential of CP that could kill the child and for the reason of unpredictable future life of their children with CP; with the intention of such emotional disturbance then after the situation become over and everyone live with lack of psychological freedom Abidoglu & Gumuscu, (2007). For most mothers, at the early age, particularly when they hear their children's diagnostic result, really it is heartbreaking, crushing and sorrow in the reality of lost hopes and dreams becomes obvious (Huang, Kellett & St John, 2009).

2.2.2. Perceived sign of depression and stress

For mothers of children with CP a lot of things could be obviously observed as a sign of depression and stress in their everyday life. As confirmed by Buming, Gunal and Tukel (2008), mothers of children with CP has show various sign of depression and stress in regards to caring and having such children with CP. Parents have feelings of sorrow and unhappiness because of realizing their children's diagnostic result (Whittingham et al., 2013). As compared with the general population, mothers of children with CP have higher levels of distress, emotional and cognitive problems, physical problems and financial strain (Brehaut et al., 2004). Mothers of children with disabilities are mainly at high risk for psychological distress because of the

multiple causes of stressors that are associated with the care giving role Seltzer, Greenberg & Krauss (1995). Cerebral palsy can have implications for psychological and physical wellbeing of the parents (Brehaut et al., 2004).

A research conducted by Marika, (1999), the result indicated that; parents especially, mothers of children with disability have significantly more negative emotional states and also significantly more depressive and warning sign repeatedly observed are; like responsiveness, loneliness, sleep disturbance, blaming oneself/ self guilt, sorrow. Even in the parents, mothers are faced a lot of stress than father, because they have to spend most of their time with the child with developmental disability at home. (Buming, Gunal and Tukel 2008) also stated that, the mother has to take on a large amount of stress because they are alone with oneself with their children in day to day life. Nimbalkar, and his colleague (2014) also confirmed that, the primary caregivers (mothers) social participation is mainly little and restricted because the questions which raised by relatives, friends and other community make them to feel inferior and uncomfortable to engaged in social event like; birth date, wedding, and social get-together+.

2.2.3. Source of depression and stress

The negative responses and lack of awareness that responded from the society for such mothers of children with CP as regards to having a child with CP are the main causes of depression and stress. Those sources of depression are become high in developing countries, like in Ethiopia. As confirmed by Singogo, Mweshi and Rhoda (2015), due to a lack of support from the family, community members and health care providers; mothers of children with CP have feeling of loneliness or socially isolated. In some cases, some shocking perception that represented by the society can neglect both mothers and their children with CP. This ignorance increase mother's psychological distress and living through blaming themselves. Sometimes, even their relatives including the child's father also lower their status and decrease the dignity of the child's mother.

Accordingly, for most mothers of children with CP, their social relationship with the members of their families, relatives and neighbors are negatively affected. Therefore, this reality increased the mother's psychosocial problems. As described by (Davis and his co-researchers 2010), there were many psychological and emotional problems encountered by mothers of children with CP. For instance, the major sources of depression are Sleep disturbance, feeling of suicidal tendency and caring their children with CP for a longer time lead to increase psychosocial problems. The

previous study carried out by Sajedi, Alizad, Malekkosravi, Karimlou & Vameghi (2010), the result demonstrated that, having a child with CP by itself is associated with higher prevalence and severity of depression among mothers of children with CP. so, having a child by itself is a common sources of depression and stress.

As represented by (Buming, Gunal and Tukel 2008), mothers' depression is also resulted from being over burdened by the demands of care giving, take home a livelihood and other responsibilities. Due to cultural beliefs, society's perceptions are for the birth of a normal child, but display negative attitudes towards the birth of a child with disabilities (Raina et al, 2005). According to Rudolph, Rosanowski, Eysholdt and Kummer (2003) also found that, the burden of care giving plays an important role in the course of anxiety for the parents.

Cultural and traditional belief, insufficient support services for mothers and their children, unsupportive interactions, and limitation of parental social relations, social isolation of the child; make the mothers to become easily frustrated and experienced psychological distress.

2.3.Care giving Challenges Experienced by mothers of Children with CP

Care giving is an ordinary duty and mandatory for parents but children with CP are required high level of care and treatment which has a burdensome psychosocial impact on the ordinary life of their mothers. Mothers' psychological distress was resulted from long term care giving duties and greater amount of energy consumed by these tasks Murphy, Christian, Caplin, & Young (2006); Myers, Mackintosh, & Goin-Kochel (2009); Yantzi, Rosenberg & McKeever (2006). Mothers who care for children with CP may experience many challenges. Because, those children with cerebral palsy needs immediate help from their mothers and most of these children are dependent with their families since cerebral palsy exist with several further problem. So, these increase the challenges on mothers in caring their children with cerebral palsy.

According to (Davis et al., 2009), he confirmed that, there are several challenges that parents face; parents indicated that caring for their child affects all facets of their life including physical wellbeing (i.e. demands on physical health), social well-being (i.e. difficulty in maintaining positive social relationships), freedom and independence (i.e. limited freedom), family well-being (i.e. pressure on marital relationships), financial stability (i.e. financial burden) and support of services (i.e. insufficient support from services).

As the researcher mentioned earlier, it was confirmed in several literature on the issue of disability, caring for a child with a disability impacts on many aspects of a parent's life, including physical, social and emotional well-being, marital relationships, and employment and financial status (Blacher & Bromley 1990; Raina et al. 2005). The traditional method of carrying on the back utilized by the caregivers might give rise to increases the back pain problem (Dambi, Jelsma & Mlambo (2015).). As confirmed by (Davis et al. 2009), he highlights that, lifting and carrying children on regular basis on their back might result in overloaded physical pain.

However, rehabilitation service is only one aspect of service usage and psychosocial supports are also very important contributors of parental well-being. In Ethiopia, there is inaccessibility of rehabilitation services which can restrict mothers how to care and support their children with CP. the most known rehabilitation centers in Ethiopia is Cheshire for physical disability, which is found in Addis Ababa. Actually the center provide primary training for three months for mothers of children with CP, but the training focuses on physiotherapy.

Unfortunately, little or no studies were conducted on the issue of psychosocial challenges that experienced by mothers having children with cerebral palsy in Ethiopia. Even there is no any published journal, thesis or dissertation in Ethiopian journal of article.

2.3.1. Restricted Social participation

It has been reported by Lynch (2007), in addition to the emotional problems, the negative attitudes of friends, relatives and the community members restrict the mothers' social interaction. These disturb the mother's psychological wellbeing to interact with other society. Communities in Africa often have a negative perception for people with disabilities because they believe that it is a punishment from the God Urimbenshi and Rhoda (2011); Wegner and Rhoda (2015; Lynch (2007). Even to utilize rehabilitation service effectively, the cultural beliefs have an effect on the outcomes of individuals with disabilities Wegner and Rhoda (2015). Parents of children with disability are embarrassed as a result of the response of other community member (Whittingham et al., 2011). Sometimes, children and their parents are excluded from any social program or social get-together because such negative attitudes can lead them to feel isolated (Bourke-Taylor et al., 2010).

On the other hand, caring for a child with CP can also have a positive impact on a parent's ability to build new social support network in nature and parents can represent motivation from their children (Davis et al., 2009). In addition to this, according to united nations development plan (UNDP 2007), their husbands left out and normally turn to extra marital affairs, neglect their wives and offer little or no support leading to marital breakdowns.

2.3.2. Physical Health problem

As long as, the high level of care required by a mothers for their child with CP with long-term functional limitations can become burdensome, and may affect both the physical and psychological wellbeing (Dambi and Jelsma 2014; Raina et al., 2005). According to Dambi, Jelsma & Mlambo (2015), the traditional way of carrying children at the back utilized by the caregivers might give rise to increasing back pain. In many cases, it is mandatory for mothers to carry their children to their physiotherapy appointments because one of the most problems that restrict access of physiotherapy services is geographic location (Saloojee et al., 2006; Larivière, Bastien & Racine, 2011). Generally, due to care giving demands and uncertainties, the challenges include psychological ones Glasscoe, Lancaster, Smyth and Hill, (2007). According to (Tonga and Duger 2008), physical health challenges are emanated from excessive stress and through constantly assisting their children in activities of daily living. In the same way, the research conducted by Wijesingh, Fonseka and Hewage (2013), the result demonstrated that, caring for a child with CP comprised of a challenging task, as their physical and emotional distress require effort, dedication and time.

Children with disability require more care, and their parents suffer more stress in taking care of them Karande and Kulkarni, (2009). In most cultures of the world, mothers are more responsible in caring their children and mainly the primary caregivers of children with disabilities are often mothers (Ones, Yilmaz, Cetinkaya, & Caglar, 2005). Take care of these children, especially those who require unusual, extraordinary care and long-term support consequences physical and mental stress for their mothers Kaya et al., (2010). Evidence showed that, mothers who take care of children with disability suffer from more severe physical and psychological complications than mothers of healthy children Laurvick et al., (2006). Of course, following the responsibility of caring children with disability has a profound impact on the life and general wellbeing of mothers (Davis et al., 2010).

It is known CP is exists in early years of a child's life but if the child grownup; the challenges become difficult and complicated to care the child. Due to different related problem or disorder, like, speech disorder, emotional and motor impairments, child becomes absolutely dependent with their mothers. It has been demonstrated by Piggot, Hocking, & Paterson, (2003), the impact of having a child with CP may change depending on the child's age. However, in other study results suggest that, the fundamental issues related to caring for a child with CP remain similar throughout childhood and adolescence, although some indicated that the level of impact on these issues may be more pronounced in earlier years (Davis et al., 2009).

2.3.3. Marital problem

Due to caring their children with disability both mothers and fathers roles are affects, but the daily lives of mothers are often extremely affected than the father, because it is known in most country of the world, mothers are usually the primary caregivers for their child. Therefore, evident show that, as a result of caring their children with CP, the quality life of these mothers of children with Cp is negatively affected Olawale, Deih & Yaadar (2013).
Previous research was also described how parents of children with disabilities are divorced due to the burden of care giving demands. A research carried out by Wade et al., (2006), confirmed that, families of children with disabilities are at least twice likely to divorce by the time the child is reached eight years old. So, the care giving demands are the cause of divorce for families of children with CP. Correspondingly, a study carried out by Rodrigues & Patterson, (2007) concluded that, couples (wife and husband) due to raising their children with disabilities who are at great risk of severe impairment could be a basis for the formation of divorce and eliminates love among them. In fact many people want to form married for several reasons including to acquire a child; however problems might be arise in marriage when the couple acquire a child with disabilities Risdalle & Singer (2004).

2.3.4. Financial burden

Caring children with CP have a lot of financial problems and due to the expensiveness of materials mothers of children with CP struggled to find these resources easily. According to (Brehaut et al., 2004), the most considerable significant resources that require to continuing caring task for such children with disabilities are many and time. Financial problem create

emotional distress and this emotional disturbance also could be a source for marital problem that experienced by families of children with CP. In addition to this, this long term care and treatment have a greater impact on mother's marital status and income. The mothers experience socio-economic challenges are resulted from the mothers' lack of employment opportunities (Borst 2010). The research conducted by (Davis et al., 2009), confirmed that, the most necessary items required for caring a severely disabled child can be the most difficult to find easily. Those materials are the basic necessities for effectively and adequately caring of those children with disability.

Due to care giving challenges mothers of children with CP leave their jobs and become unemployed. Losing work opportunity and being unemployed which experienced by mothers are because of the amount of time spent in caring their children with CP. As confirmed in previous studies that carried out by Murphy et al., (2006); Thrush & Hyder, (2014), financial burden occurs because of mainly parents leave their jobs and unable to do works this was occurred due to the amount of time they spend to care their child. Similarly, financial problem mostly emerged when mothers were unable to found jobs due to the amount of time that they were expend a longer time in caring their children every day (Bourke-Taylor et al., 2010).

On other the hand, due to spending more time on caring their children with CP, mothers' economical incomes become decreased. Due to this, they seek to found financial funds from different private organization. But, due to lack of awareness, the organization cannot accept their ideas and disqualified their children to receive financial assistance. These was confirmed in various previous studies e.g. (Resch et al., 2010) reported that, lack of awareness that made by different organization to raise fund for financial donation for mothers of children with CP are argued that they do not qualify for financial aid because of unmeet for range of poverty to receive financial assistance. In the same way, the research conducted by Saloojee et al., (2006), described that, mothers are faced bureaucratic problem as one of the greatest barriers to getting the grant, as they were often confronted with long waiting periods and were repeatedly provided with the incorrect forms. Additionally, some mothers also expressed that lack of awareness that their child was qualified for receive a funding service, mothers also unable to know where and how to apply for the grant and a lack of the necessary documentation (such as identity documents

or birth certificates) to apply for the grant are a common problem for mother to receive financial aids from different organization (Saloojee et al., 2006).

Likewise, access to funding is also a common barrier to care giving, as individuals struggle to access financial aid in order to cover the expenses that accompany their child's disability (Davis et al., 2009). Because of bureaucracy, caregivers were struggled to apply and obtained access for financial supports from different governmental and nongovernmental organization. As conducted by (Davis et al., 2009: McManus et al., 2006) that, actually the process of submitting an application for financial aid is often time consuming and exhausting for caregivers.

2.4. Mothers interpersonal relationship with their children with cerebral palsy

Parent and child interactions also influence the degree to which a family who has a child with special needs experiences stress. To have a better interaction among mother and their children with CP, the mothers should develop positive attitudes to accept their children's disability. One of the challenges that existed during mother-child interaction is the occurrences of speech disorder parallel with cerebral palsy. According to Barfoot, Meredith, Ziviani, Whittingham (2017), optimistic, encouraging and healthy parent–child relationships contribute for best possible child development but less is currently known about associations between the parent–child relationship and development for children with cerebral palsy. Children with physical disabilities, including cerebral palsy, are at increased risk of disrupted relationships with their parents Heffron (2000).

Depending on the child's ability to interact and communicate with their parents, parents may have to adjust their interaction styles to meet the needs of their child Pueschel, Bernier, & Weidenman (1988). Mothers who are unable to obtain some guiding cues or feedback from their child may experience further stress and which limits their interaction (Fewell, 1986). Many mothers of children with CP need a good sense of facial expression from their child but some children with CP cannot express their emotion, either they are happy or not. Through experience many parents of children with disabilities adapt the way they interact with their child, but some families need help in communicating and interacting positively with their child (Bailey, & Simeonsson, 1988). In addition to speech disorder, due to fine motor disorder, children with CP cannot use sign language effectively to communicate with their parents.

Mothers of children with a disability have reported difficulty understanding some of their child's cues Bailey & Simeonsson (1988). In a longitudinal study by Goldman and Johnson-Martin (1987), confirmed that, parents' perceptions for their children with disability are evaluated concerning the readability of their child's expressions of emotional distress, cheerfulness, and interest. Both mothers who have children with and without disabilities perceived their infants to be equally readable for cues regarding distress and happiness (Bailey & Smeonsson 1988). On the other hand, Bailey & Simeonsson also described that, mothers who have children with special needs were not confident of their children's indication of feeling as regards to knowledge and attention in social interactions.

Children with CP seldom motivate for exchanges in spoken communication with their parents and other individuals, unable to being responsible for a specified task, while adults introduce topics and start most conversations Harris (1982). As described by Light et al., (1985), such children with CP mainly construct and respond a yes/no responses and acknowledgements of others' expression and rarely utilize ask questions as well as instructions. In the intervening time, the family members of children with CP and other familiar persons exercise sophisticated instruction for them such as requests to give concentration, requests for objects and procedures, and requests for incoming message (Light et al. 1985). Such patterns of interaction have been observed in children from preschool to late teens, suggesting that children with CP often fail to develop a full range of communication skills. Possible explanations for this relate to different areas of children's development. Firstly, the presence of a general motor impairment may have consequences for communication development.

In most cases, the motor impairments that existed on the children in relates to CP affect children's physical ability to control objects using their hands, to play and do activities independently, and to carry out actions associated with their daily living. If such children not be capable to do things independently in various conditions, parents are responsible to assist and guide them physically and emotionally in daily living activities, leading to the more frequent proximal interaction that has been observed Brooks-Tayelor and Lewis (1984). The lifestyle and practice of supporting their children may include some degree of control and teaching children how and when to perform things, may spread from general physical assistance to specific way of exchanging their ideas. Therefore, if the higher amount of dominance in conversation as well as

guidelines is covered by adult may come up with little degree of the child independence in accomplishment of the task; reduce their decision making opportunities and communication skills Kogan (1980).

The reason for high level in conversation is observed in mothers' speech because, mainly mothers does not supporting their children as well and they have been estimated that all the things including physical activity which they perceive to be lacking in their children's development could be stimulated by therapists in various programs and their children to produce certain target behaviors Bell (1971). Such adult domination in any daily living activities would be a main reason for children to have little opportunity and to be dependent in a full range of interaction skills.

As confirmed by (Harris 1982), children mostly utilize their natural modes of communication, such as vocalization, gesture and body movements, and rarely use their augmentative system, unless requested to do. CP can have an effect on a child's ability to produce clear signals that are consistent over time. This lack of contingency may start from the very beginnings of interaction, with problems affecting the establishment of mutual gaze, as well as the later production of gestural, vocal, and verbal signals for intentional communication. It is likely that parents should adapt their communication to realize some feelings of effectiveness concerning their interaction with their children Dunst (1985). They may offer their children only communication opportunities in which they can predict their children's signals. However, as the number of signals that parents can predict may be very limited, the range of opportunities they can engineer for their children may be very restricted.

2.5. Possible coping mechanisms employed by mothers of children with CP

According to Lazarus (1993) defined coping as ''the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands appraised as taxing or exceeding the resources of the individual''. According to Lazarus and Folkman (1984), coping efforts serves two main functions: management of the person-environment relationship and regulation of associated stressful emotions. How parents were cope with stress are particularly important because coping influences the emotional/ psychological outcomes of a stressful event. The result of one literature review of European Journal of special education Research by Faijullah & Ansar

(2016 P. 44) concluded that, ‘‘sometimes coping can have a direct impact on psychological well-being, or act as a moderator between psychological well-being and the stressor. Studies have shown that use of problem focused coping strategies results in lesser psychological distress and better mother-child interaction while use of negative emotion focused coping increases the possibility of parents experiencing depression and stress-related problems’’. It can facilitate problem-focused coping if it is used to manage negative emotions that would otherwise impede problem-focused activity (Lazarus & Folkman, 1985).

As reported by Cheshire and his colleagues (2010), qualitative descriptions suggest that positive reinterpretation may promote improved psychosocial well-being among mothers caring for a child with CP. For example, focusing on the positive aspects of a situation emerged as an important theme. Indeed, other studies have reported that parents of children with disabilities cope by focusing on the positive aspects of the child, their child's abilities, parents' love for their child and drawing strength from their child's happiness and achievements (Beresford, 1994; Brown & Hepple, 1989; Turnbull, 1985).

The research article which were conducted in Ethiopia on resilience and success of persons with disabilities in Ethiopia, clearly described that, "*the strategies used to cope and overcome environmental stressors and difficulties tend to be more or less similar across the different disability groups"* Tirusew Tefera (2005, p.23). likewise, As confirmed by Croot et al., (2012), as cited in Diseko (2017), mentioned that, ‘‘strategies of acceptance of the child, faith and social support is considered helpful for mothers in managing the challenge of raising a child with disability.

However, Some of a common coping strategies that employed by mothers of children with cerebral palsy are as follows;

2.5.1. Religious coping /faith-healing/ or spiritual practices

This is described as a powerful feature that contributes to adaptation in family members, during challenging situation. A number of families of children with disability turn to religious coping for help after their child is diagnosed with a disability and this can give a potential to reduce the parents stress Greeff and Nolting (2013). As clearly described by Kamaruddin & Mamat (2015),

most probably parents of children with disability are to turn towards faith healing interesting in praying for reassurance and increased religious activities to feel less stress. According to (Bayat, 2007), argue that developing and practicing a spiritual belief system is one way of utilizing adequate coping approach to deal with stress and towards the care giving responsibilities of their children with disability. Furthermore, according to Poston & Turnbull, (2004), mothers are gain strength from their personal faith which provide and allow them to accept their children's disability as well as to regulate challenges that associated to caring their children.

Religion and spiritual practices have numerous benefits which assist individuals in the process of coping stress. A number of studies have every time consistently confirmed for the significant of religious coping. For instance, as confirmed by Koenig, McCullough, & Larson, (2001), being consistent in practicing religious way of life provide greater positive effect such as life satisfaction, happiness, improving self-confidence and other indicators of well being. In the same way, according to Biesinger & Arikawa (2007), Parents who are motivated by fundamental religious beliefs are more likely to demonstrate superior levels of cheerfulness. Likewise as reported by Kausar, Jevne & Sobesy (2003), families who have look forward to future life are more simply capable to adapt their life in view of different perspectives with their experience of having a child with a developmental disability.

A previous study conducted by Goren (2015), also deals with how families of children with disability spiritually made sense of their situation. In this study, parents were found to consider their children with disability as an designation of works that given from God to be kept their children in safe and secure way of life, they felt as they are blessed mothers, believed that their children with disability would provide them with a ticket to heaven, they thought that they were living with the correct angel of the God, felt proud to be parents of a heavenly child; and felt their children brought blessings to the house, luck to their lives, and peace to the family.

Religious coping can be positive or negative it depends on the knowledge of the child's family. According to Pargament (2001), religious or spiritual coping are may obvious a person's think he/she are obtaining support from the higher power and believing that higher power will never leave them alone or cannot provide shocking things to them, they have faith in God or believe that He will guide and help them cope with difficulties. (Pargament 2001) found that, positive religious coping has healthier faith outcomes like closer relationship with God whereas; negative

religious coping was associated with superior depressing and disappointing effects with poorer religious outcomes like feeling of left alone by god, hopelessness, feeling of inferiority etc. On the other hand, individuals consider acquiring such children with disability as a punishment from God, and they make negative religious reappraisals in the face of difficulties (Pargament & Brant, 1998).

Religion also emerges to have external influence in regards to serving people deal with stress as their negative emotions. Some of these strengthening good behaviors include prayer, reading the bible/holy Quran/ and presenting consistently on religious activities. According to Shumaker (1992), people who internalized religious values are more readily to faith as a supportive way of coping with stress and when they are in opposite to intense these religious values and they become largely experienced in stress. In addition to this, as reported by Gray (2006), religion coping strategies are some of the most widespread strategies and frequently employed by parents of children with disability. Therefore, employing helpful coping methods, such as religion, forwarded to positive adaptations with positive outcome and improved the general wellbeing one's life and the needs of the family Norizan & Shamsuddin (2010).

2.5.2. Receiving Social support

Social support defined by the description of national cancer institute's dictionary of cancer as "a network among family, friends, neighbors, and community members that is, making support accessible to individual through social ties and providing emotional, physical, and financial help for the concerned bodies" (www.cancer.gov). Likewise, social support refers to the provision of psychological, material resources or financial support which afforded by a social network for help individuals to cop and deal with stressful situation.

As confirmed by Southwick, Vythilingam, Charney (2005), extremely positive social support can improve the individual's capability to cope and resilience from stress, help to keep against developing depression, decrease the functional consequences of psychological disturbance. As the representation of theoretical model of social support which was clearly described by Charney (2004), as cited in Fatih et al., (2007), the amount of social relation relationship and the frequency of a personal interactions with the community member and a practical support with

psychological and moral support (such as offering worship and understanding others) and material support (provision of contributions money or assistance with child care) are included.

According to Hyman, Gold and Cott (2003), a good social support is passionate for practicing self-esteem support (the individual recognize that he or she is valued by others) and appraisal support (the individual perceives that he or she is capable of receiving counseling service when coping with demanding situation) are the most helpful in preventing the stress. On the other hand, having poor social support has been linked to sadness, helplessness and loneliness which maximize the risk of depression, suicide, alcohol use, cardiovascular disease, and altered brain function. As the evidence of one study Grav, Hellzèn, Romild, Stordal (2012), those individuals who have well-built social and psychological support are less likely to be die than those who lose such sufficiency strong relationships.

A number of researchers were confirmed that, employing social support as a coping mechanism to resilience from stress enhance individual's social and psychological well being. It has been argued that having a prosperous and healthy social interaction can decrease the rate at which individuals involve in risky behaviors, avoid negative appraisal or decision for life, and increase being of faithfulness and treatment adherence Rozanski , Blumenthal, and Kaplan (1999); Fontana, Kerns, Rosenberg, and Colonese (1989). Generally, strongly committed hardy peoples devoted to use active coping strategies to deal with demanding and worrying life situation Moos, and Schaefer (1993).

Sometimes peoples may provide guidance and counseling service, suggesting or providing new information about the issue, and recommending individuals when making decisions or great changes in one's life. So, due to receiving this type of support, their level of anxious will become little and resolve their life related problems successfully and powerful to reach their goals Ko,Wang , and Xu (2012). Having a strong and well build network of social support have several benefits, including the following: improving the ability to cope with stressful situations, alleviate and eliminate the effects of emotional distress, upholding lifelong healthy psychological wellbeing, enhancing personal self-esteem, lowering feeling of suicidal, promoting healthy lifestyle behaviors and encouraging adherence to a treatment plan.

To practice this active coping strategy to families of children with CP, the stress is a set of changing conditions associated with the child's disability. Resource as coping strategies which includes; an individual's knowledge and skill, family system resources (cohesion) and social support are included. Perceptions may include optimism, resilience, and locus of control. A person with a strong sense of rationality is likely to appraise the stressor in a more positive light and perceive it as a challenge, whereas an individual with a low sense of coherence would more likely perceive the stressor as a threat (Olsson & Hwang, 2006). Twoy, Connolly, & Novak (2007), found parents effectively coped when they used informal and formal social support networks. As confirmed by Siman & Kaniel, 2011; (Twoy, Connolly, & Novak, 2007), social support can eliminate stress by increasing parents' feelings of control and appeared to be a large part of the external coping strategies for the family.

Scholars agree that accessibility and utilization of external support service serve as a buffer in adverse situations. The researcher supposes that providing appropriate help and support services have an extreme positive outcome for the primary caregivers (mothers) of children with CP. This social support service can help mothers to decrease the intensity of stressful life situation.

2.5.3. Emotion regulation /patience/

As confirmed by Tugade and Fredrickson (2007), the activation of positive emotions while coping with challenges can foster resilience. Having a positive emotion can allow people for a flexible attention, which can in turn improve one's wellbeing. Therefore, through time and with repeated experiences of positive emotions, this broadened mindset might become habitual (Tugade and Fredrickson, 2007).

The extent to which the parent's capacity to be emotionally available and ability to consistently implement parenting practices based on fair and reasonable values and expectations is directly influenced by parent's emotion regulatory capacities (Harnett and Dawe, 2012).

2.5.4. Accepting the child's disability

According to Greeff and Nolting (2013), also confirm that, next to the birth of a child with a disability, parents should adapt and adjust the situation to accept their children's disability. Developing a Positive coping technique through employing effective problem-solving skills and

positive perceptions towards their children with CP are directly associated with effective family adaptation and resiliency Norizan & Shamsuddin, (2010). Parents who have children with developmental disabilities in China most frequently employed strategies to coping stress which included like accepting their children's disability, positively dealing the demanding situation in related to disability, optimistically reinterpreting and growing with the experience which could be helped them for stressful condition, and planning to deal with the related stress Wang et al., (2010). Developing awareness for the truth concepts of disability by parents is a key element that could help families of children with disabilities to cop and adapt in care giving of their children with disabilities Ross and Deverell (2004). According to Sharief (2014), parents are become challenged and find it quite stressful to accept the disability which exist in their children.

Similarly, in our country Ethiopia, one study was also conducted by a famous professor (Tirusew Tefera, 2005), the results are clearly stated for the significance of accepting the child's disability as follows; accepting and tolerating personal limitations by oneself, being strength in religious or praying are the major elements for unfolding and strengthening resilience. If a child has severe impairment like cerebral palsy, which forwarded to greater dependency on the families, it creates greater discomfort feeling by mothers of children with CP. Due to this, family also tend to perceive those child's as valueless as compared to the other children without disability. It is therefore paramount importance to educate the community on the issue of disability to remove their negative thoughts and untruth ideologies, thereby promoting the adaptation of care givers (Ross and Deverell, 2004). Of the same view is the research conducted by Mcconnell, Savage, & Breitkreuz (2004), assets that, positives adaptation employed by parents who raised children with disabilities is in any case influenced by the perception of the community members' accommodation skills and capabilities for person with disability.

According to Bayat (2007), recommend that, developing and increasing positive perception for a stressful condition could be a shock absorber for the stress associated towards the responsibility of caring for a CWD. As point out by (croot et al., 2012, as cited in Diseko 2017, p. 44) that the negative ideas about disability arise from caregivers previously held ideas about disability and those of close association like family and society; reframing the disability as a medical condition or a blessing empower parents to challenge this view and in doing so facilities acceptance of the child.

CHAPTER THREE

RESEARCH METHODS

Introduction

In this chapter, research design, study Site/area, population, sample and sampling techniques, sample size, data gathering instruments and procedures, and data analysis techniques are sequentially arranged.

3.1. Research Design

The main purpose of the present study was to explore the psychosocial challenges encountered by mothers having children with cerebral palsy in Addis Ababa, at Cheshire service Ethiopia. The present research issue is qualitative in nature, so qualitative approach was employed as the research method for this study. Qualitative research offers an in-depth and a great deal of detail investigation, comprehensive understanding of phenomenon, human behavior or social problems as well as their attitudes in natural setting Gonzales et al., (2008). Qualitative research investigates a phenomenon considering the context of people's everyday lives. It attempts to understand and explain the world from participant's points of view Draper (2004).

To achieve the above purpose, phenomenological research design was employed. The researcher preferred this design because, as stated by Marshall and Rossman (1999), as cited in Madeline (2010), the primary goal of phenomenology was to encapsulate the full meaning of the participant's experiences as shared in their own words. Correspondingly (Rossman & Rallis, 1998, p. 68), described the goal of phenomenological research "seek to understand the lived experience of a small number of people". Similarly, as confirmed by Creswell (2013), phenomenology is relevant where information is required directly from those experiencing individuals or phenomenon under investigation. This type of research design is significant for this kind of research because it is better to gain first hand information as regards to mother's psychosocial challenges. On the other hand, for the realities of mothers lived experiences towards their psychosocial challenges and better when the information is expressed by them.

3.2. Study Site/area

The study was carried out in Addis Ababa, at Cheshire service Ethiopia. The study area was purposely decided by the researcher to work there because many children with cerebral palsy go there with their mothers to receive developmental physiotherapy service. Cheshire service Ethiopia is located in Addis Ababa at yeka sub city administration around salete-meheret. Cheshire service Ethiopia was established in 1962 by the grand children of the late emperor Haile Selassie and with technical support of Captain Leonard Cheshire. It is a local independent NGO while playing a leading role in physical rehabilitation for person with disability; with its objectives for the enhancement of social functioning and inclusion of persons with disabilities in all aspects of life.

Actually the main office is found at Burayu /menagesha/. But, the Salete-Meheret is its branch and provides developmental physiotherapy service for children with CP, spinal bifida and others physical disability. In addition to the provision of such services for children; they also accessed home based intervention through affording physiotherapy skills training for mothers. After receiving the training, such mothers of children with CP provide physiotherapy service for their children at home for six days and one day per week their children attend the services in the organization by physiotherapies professionals.

3.3. Population, sample and Sampling Techniques and sample size

3.3.1. Target Population

The target populations for this study were biological mothers of children with CP. particularly; those biological mothers at the present time their children with CP who are attending developmental physiotherapy service in the study area are the target population for the present study. Most mothers of children with CP were goes to the center to attuned developmental physiotherapy services for their children with CP. According to Cheshire service Ethiopia, in the present time, the total numbers of children with cerebral palsy who are attending physiotherapy service in the center are 155 (one hundred fifty five) among these, the majorities are biological mothers. So, those biological mothers of children with CP who are voluntaries to participate in this study were preferred as a participant for the study because they capable to explain details in regards to their psychosocial challenges from their initial reaction to their present life.

3.3.2. Sample and Sampling Technique

In the present study, purposive sampling method was employed to identify respondents who fit the purpose of the present issue. Thus, the researcher can decide and either the participants have a potential to share significant and meaningful experience concerning on the specified phenomenon under investigation. The reason that the researcher focused on the participants' common experience to be a sample are because, individuals who participate in the phenomenological study should be selected by their significant, meaningful and common experiences of the phenomenon being studied (Cresswell, 2007; Moustakas, 1994). Accordingly, a phenomenological study requires a relatively homogenous group of participants (Creswell, 2007). Therefore, the respondents were identified by their nature of common experiences who meet the inclusion or eligibility criteria which are presented below.

In addition to this, criterion-based selection is commonly used in a sampling method and it becomes more necessary in phenomenological studies. Therefore, in order to select a group of participants, some common inclusion criteria were arranged by the researcher.

Therefore, the following criteria were used for the inclusion of participants in this study:

- Mothers who are interested and volunteers to participate in this study.
- Mothers of children with CP who must be a primary care taker of the child.
- Biological mothers of children with CP who must be their children's are currently attending developmental physiotherapy service at CSE.
- The mother and a child with CP must live in the same residence/home.
- Mothers of children with CP who must be a fluent Amharic speaker.
- Mothers of children with CP who can show their child's medical diagnostic assurance certificate which demonstrate the child as having CP.

3.3.3. Sample Size

In qualitative research, the size of the sample tends to be small in number because of to emphasis on intensive contact with respondents and the findings are not expected to capable of being generalized. According to Fawcett and Garity (2009), an adequate sample size in qualitative

research is one that sufficiently answers the research question, the goal being to obtain, suppose rich in information and it is determined by researcher to meet the objectives of the study.

Sample sizes for phenomenological research generally are not large due to in-depth nature of the study; even scholars recommendations for sample size are vary, a sample of 3–10 participants is usually considered appropriate (Creswell 2007; Polkinghorne 1989). As suggested by Boyd (2001), research saturation can typically be attained with 2 to 10 participants. Creswell (1998, p. 65), also recommended for the sample size in phenomenological study involve "long interviews with up to 10 or 5-25 participants are enough." As Morse (1994), at least six respondents are enough for phenomenological study.

From the above varied recommendation among scholars, the researcher realized that, there is no strict rule for a fixed number of participants in qualitative research. The required number of participants could be decided by the researcher and depends on when saturation is reached since; the fundamental goal of qualitative researchers is for the attainment of saturation. Hence, for the purpose of the present study, a total of thirteen (13) biological mothers of children with CP were participated in the study. The reason why the researcher selects those biological mothers as a participant for this study; because they can give details and accurate information about their lived experience in regards to their psychosocial challenges as having children with CP. In addition to this, it is better to understand their psychosocial challenges by the lens of the participants.

3.4. Data Collection Tools

In this phenomenological study, the data collection tools that were employed are primarily an in-depth semi-structured interview and focus group discussion. For the present study, an in-depth interview was the major data gathering tool. It is more typically applicable in phenomenological research by a direct conversation with participants. In-depth interviews are a common method used by a phenomenologist for gaining access to individual's life world (Creswell, 2007). From the total of 13 participants, seven (7) respondents participated in face to face interview in person and the remaining six (6) respondents participated in FGD. Data collection was done in the study area which are the most safe and convenient place for the participants.

3.4.1 Interview

An In-depth interview is the most common qualitative data collection method that involves direct, one-to-one and it mainly takes place face-to-face involvement of participants (Creswell, 2007). Usually, interviews are conducted with a group of individuals who have first-hand knowledge of an event, situation or experience. So, biological mothers of children with CP have first-hand and detail information on the current issue. After acquiring permission from the study participants the voices of all interviewee were recorded and each individual interview was lasted between 60 to 90 minutes but the duration was depends on the ability of mothers in explaining their own lived experiences. Initially the recorded responses were transcribed to written notes in Amharic and subsequently translated into English for detail analysis.

At the beginning the researcher was arranged a semi-structured interview guides and all of the interview questions were open ended, which allow an open dialogue (Appendix A). The interview guides also contained probing questions (for instance, can you mention them? and please explain more about it?). Furthermore, the follow-up questions were also conducted to clarify the voices of participants under investigation.

So, these open ended in-depth interview guides were arranged to collect data from seven (7) biological mothers of children with CP to realize their psychosocial challenges. Primarily, those interview guides were prepared by the researcher depending on leading research question to meet the general objectives of the present study. Originally the interview guides were prepared in English then translated to Amharic language.

Generally, the interview guides have two parts. The first parts of the interview guides were focused on demographic characteristics of participants. In order to describe participants evidently, demographic information was also gathered clearly from the study participants. Which were consisted of 10 items that indicates, mother-child relationships, mother's marital status, age, educational level, occupation and the Child's age, sex, grade level, age of the child during screening, and number of siblings were included. The second sections of the interview guides contained the main part of data gathering tools, which were focuses on four major areas. Such as, to explore the psychological challenges of mothers, to examine the mother-child relationships, to find out the care giving challenges that experienced by mothers and coping mechanisms that employed by mothers of children with CP were included. During interview session the

respondents' facial expression and gesture were also added in the form of field notes then later added in to transcripts.

3.4.2 Focus Group Discussion (FGD)

The second data collection tool that was employed for this study was Focus group discussion (FGD). The reason why the researcher preferred this data gathering instrument because it provides better access for respondents who are not speak openly and usually fear in expressing their ideas freely in individual interview. According to Yin (2003), sometimes some respondents unable to give details for the realities of their lived experiences due to this they cannot address sensitive issues. Similar to interview, the participants who participated in FGD were biological mothers of children with CP and the sampling criteria that was mentioned earlier was employed for FGD.

In the selection of participants who participated in a FGD the researcher was considered their homogeneous knowledge and background experience because, the commonality of participants background experience play a vital role for the finding of the study. As confirmed by Khan and Manderson (1992), Participants are typically selected to participate in qualitative research based on clear criteria, such as their background knowledge, personal life-experience, particular personality or role in a specified group.

For FGD, it is recommended that the size of the group include between six and twelve participants, so that the group is small enough for all members to talk and share their thoughts, and yet large enough to create a diverse group (Lasch et al., 2010; Onwuegbuzie et al., 2010). From the total of thirteen (13) respondents, six (6) mothers of children with CP were participated in FGD and all of those six respondents were discussed in one group. Before starting discussion, the researcher was introduced himself, the main purpose of the research, the required time for discussion and their rights during FGD.

3.5 Data collection procedure

After the interview and FGD guides were made ready for administration, the researcher gained approval of permission letters from Addis Ababa University department of special needs education to the concerned bodies (CSE). Then goes to study area and ask the administrative

head of CSE to conduct the present study in their organization. After a few days they express their permission by telephone. Then after gaining acceptance from the organization; the researcher discussed the detail of the research issues with the organization's physiotherapist coordinator and formed an agreement. Subsequently, the study participants were selected based on the standardized criteria.

At the beginning of data collection, the researcher explained the main purposes of the study, the participant's right in the data collection process, ensuring that, their participation would be by their volunteers, and obtained their written informed consents which were signed by all respondents. The researcher also described and ensure the confidentiality of their responses and only applicable for the academic purposes of the present study.

As confirmed by Seidman (2006), suggested that, it is necessary to build amity with the participant during the data collection. So, during interview and FGD session, the researcher has developed appropriate relationships with the study participants because of establishing a healthy relationship with participants make them feel more comfortable, so they can produce more thoughtful responses, especially regarding sensitive issues. In addition to this, the Researcher also shared his own experience about the phenomena during the investigation because; it is necessary to allow the participants to develop confidences in sharing details about their lived experiences freely.

During data collection session, the researcher was never misleads the participants by any means or gives wrong impression about the issue. Finally, after requiring a formal agreement which signed by all participants, the researcher used audio recorder in the interview and FGD session. The data collection process had continued until data saturation has done or reached. During data collection session, the researcher gave sufficient time and equal opportunity to all participants to discuss and share their ideas freely. At the end of the data collection session, the researcher thanks all participants for their active participation in the study.

3.6. Data Analysis

The raw data that was collected from mothers of children with CP were interpreted and analyzed thematically. All interviews guides were carried out in Amharic language and the recorded voices were

transcribed verbatim, then after translated in to English. For the clarity of the language used, the English version of translation was repeatedly checked by university advisor, two MA holders in English department who worked at BCTE and MTU. After the researcher was carefully and repeatedly listen the recorded voices to gain a general ideas of participants; subsequently, interpreted and analyzed through locating the original sources by linking data to the research questions. The transcribed data were reviewed again over for its accuracy and reliability.

In addition to this, field notes were taken after the interview and FGD to compare with the transcribed text. The responses were categorized and grouped together by similarity of content in meaningful units. Analysis was continued until saturation was reached. The researcher was gave code for all key ideas that presented in the FGD and in person interview. For the reliability and validity of the finding, the researcher was cross checked the data offers from different method of data collection tools.

3.7. Validity and Credibility

In this study credibility was achieved through extensive review of literature regarding psychosocial challenges experienced by mothers to establish the extent to which to show the relationship of the findings of the present study with the past studies. The researcher also had frequent consultation with the advisor at the university. Finally to ensure honesty among participants, the researcher ensured that, their participation would be by their voluntaries through ensuring confidentiality of their responses and only applicable for the academic purposes of the present study. Before data collection the researcher obtained written informed consents which were signed by all respondents.

In order to check the accuracy and reliability of the data collection instruments and for the clarity of the language used, the English version of translation was repeatedly checked by university advisor, and other two MA holders in English department who worked at higher learning institution. For the reliability and validity of the finding, the researcher was cross checked the data offered from different method of data collection tools. During data collection session, the researcher was never misleads the participants by any means or gives wrong personal impression regarding the issue. After the researcher was carefully and repeatedly listen the recorded voices to gain a main ideas of participants;

subsequently, interpreted and analyzed through locating the original sources by linking data to the research questions. The transcribed data were reviewed frequently for its accuracy and reliability.

3.8. Ethical consideration

The participation in this study was by the participant's interest, volunteer and free from any sexual harassment. Keeping participants' right to confidentiality and privacy has been the central principle of the researcher. The researcher has ensured that, participation in the interview and FGD sessions through keeping them from any physical, mental, emotional, social or economic harm and that their responses are held confidentially saved in a secured place. The researcher has never misled, deceive or misguide participants. Before proceeding to data collection, the researcher obtains informed consent that has been signed by all participants. This requirement is usually part of the study approval issued by an ethics advisory board.

Chapter Four

Findings of the Study

Introduction

In this phenomenological qualitative study, the researcher tends to explore the psychosocial challenges encountered by mothers having children with cerebral palsy that assisted by an interview and focus group discussion guides. Due to this, from the total of thirteen (13) respondents those participated in the present study, the researcher conducted face-to-face interview individually with seven (7) respondent mothers and a very hot group discussion has done with the remaining six (6) mothers of children with CP. Then, after the researcher gain permission which signed by such respected voluntary study participants; the data collections were supported by audio tape recorder.

Therefore, the major findings of the present study have been presented and organized in to the following main thematic areas:

- Demographic characteristics of participants
- Psychological challenges faced by mothers of children with CP
- Mothers interpersonal relationship with their children with CP
- Care giving challenges experienced by mothers of children with CP
- The possible coping mechanisms that employed by mothers of children with CP

Table 1. Demographic characteristics of Participants

No	Participant's Pseudonyms	Parental status	Marital status	Mother's Age in year	Educational status	Mother's occupational status	Child's sex	Child's age	the child's age during screening	Child's grade level	Number of siblings		
											M	F	T
1	MCP 1	Biological mother	Married	31	4th	Unemployed	M	3.6 year	At 9th month	-	2	1	3
2	MCP 2	Biological mother	Divorced	30	10th	Unemployed	M	3 year	At 3rd month	-	-	-	-
3	MCP 3	Biological mother	Married	28	10th	Unemployed	M	3.5 year	at birth	-	-	-	-
4	MCP 4	Biological mother	Married	28	10th	Employed	M	7.4 year	At 1st week	Kg 3	-	-	-
5	MCP 5	Biological mother	Married	26	10th	Unemployed	M	2 years	At 9th month	-	-	-	-
6	MCP 6	Biological mother	Married	25	10th	Unemployed	F	3 years	At birth	-	-	-	-
7	MCP 7	Biological mother	Married	36	9th	Unemployed	M	3 years	At 1st week	-	-	1	1
8	MFGD1	Biological mother	Married	35	6th	Unemployed	M	1 years	At birth	-	-	-	-
9	MFGD2	Biological mother	Divorced	30	10th	Unemployed	M	4 years	At 3rd week	-	-	-	-
10	MFGD3	Biological mother	Married	26	5th	Unemployed	M	3.4 years	At birth	-	-	-	-
11	MFGD4	Biological mother	Divorced	33	8th	Unemployed	M	5 years	At birth	-	-	-	-
12	MFGD5	Biological mother	Married	29	7th	Unemployed	M	2 years	At 1st month	-	-	-	-
13	MFGD6	Biological	Married	32	10th	Unemployed	M	2.5years	At birth	-	-	-	-

4.1. Demographic characteristics of participants

The sample size for this study was n = 13 which comprised of merely mothers of children with CP. All of the study participants met the standardized criteria of selection which were a pre-condition or eligibility criteria to be a sample for this study. As indicated on the above table (Table 1), from thirteen (13) participants, the first seven (7) respondents are participated in the interview session and the remaining six (6) participated in focus group discussion respectively. All of thirteen (13) mothers of children with CP who participated in this study are biological mothers and voluntarily participated. All of the participant's children are currently attending developmental physiotherapy service in the study area of the present study (CSE). Except one, all participants are married and their ages ranged are between 25 to 36 years old. From the total of thirteen (13) study participants, eight of them completed grade ten (10) and the remaining are between grade four (4) and nine (9). Unfortunately except one, the remaining twelve (12) respondents are unemployed. From the total of thirteen participants, three of them are divorced and the other ten are married. The age ranges of the participants' children are between two (2) to seven (7) years and except one child, the remaining twelve (12) children are not entered to school. Likewise, except one child, the others children are male.

To ensure the confidentialities of the voices of study participants; the researcher used pseudonym in reporting of findings in order to protect the identity of the study participants. Accordingly, in this report the voices of participants were italicized.

4.2. Psychological challenges faced by mothers of children with CP

The researcher started interview from the concepts of CP before the birth of their child's with CP and the response of all mother of children with CP were; they had not had any concept or ideas in regarding to CP. Even after the birth of their children with CP, most of the participants were expected as a health problem and did not understand as a permanent disability. They also assume that, CP can be cured by medical treatment like other diseases.

One respondent mother of children with CP expressed her perception for the concepts of CP as follows:

''*During* birth, my *child was screened out as having CP. During that time, I was not well informed for the result of my child's diagnosis. Even my husband was afraid to tell the realities of my child's condition. Before that I didn't haven't the concept of CP and I don't know what CP is. After a few days, when I looked my child, he does not look like other healthy children and cannot show the character of a healthy child. Even he shows a squint eye, improper way of sucking; his skin was look like yellow color and loses some developmental responses. These initiated me, to focus on the child and I supposed he might have some health problem, like lack of oxygen during birth. Afterward, I decided to go to hospital to check his health condition by health professionals. For the fact, I was believed my child will return to the normal condition after gating appropriate health service because, I had no any real information for about his condition. At the time of diagnosis, when I heard the concepts and realities of CP from the doctor, it was really painful and difficult to accept the realities; afterward, I became worried, disturbed, felt hopelessness and depressed about the situation."* **MCP1**

In the beginning, the researcher raised discussion point from the participants view as being of mothers of such children with CP and unanimously all participants approved for the complexity of their life but such challenges are absolutely varied among them. For the reason that, due to the challenging nature of this disability; such children with CP are mainly needs a unique and immediate care. So, possibly it has a negative impact on mothers' life. As the description of the study participants, being a mothers of children with CP add overloads and eliminate their quality of life. Accordingly, this leads them to develop inferiority, feeling of tension for the child's future life and being of loneliness and other depressive condition. In general, they face various challenges and greater disturbances which includes, restricted them from having a meaningful participation in the societies, marital and health problem, disturb emotional wellbeing, add burden on home based daily living activities and others. Usually they complain and blame themselves as having children with CP. In most cases, they lost a lot of work opportunities and become unemployed.

In the group discussion as narrated by one respondent mother for being a mother of such children, she described her thoughts as follows:

"Being a mother of children with CP is difficult and complicated because mothers are completely live for their children with CP and nothing to consider her life. Their full time responsibility could be caring their children with CP and caring of such children is very exhausting and time consuming. Due to this, mothers cannot carry out any work out of the home rather than caring her child with CP. As a result of this, mothers should left her full time for caring her child with CP and mostly nothing to think her life. In addition to this, she hasn't any social contact and eliminates her involvement with others even with her relatives. It also has a profound effect on marriage/couple relationships/, physical health problem and psychological distress. Actually being a mother of such children with CP is heartbreaking... Forever the time, mothers were confused and solicit themselves, like, what was our wrong doing? Why god gave us such disabled children?" **MFGD 4**

4.2.1. Mothers initial reaction

The researcher also asked the initial reaction of mothers during their child screened as having CP. The responses of all seven respondent mothers of children with CP who participated in one to one interview had a feeling of frustration, stress, depression, shocked and disheartened for the unexpected as well as unbelievable diagnostic results of their children. All respondent mothers were distressed and sorrowful for the result of diagnosis and they were disturbed, upset, and anxious for a longer time. Due to suffering in a greater psychological distress, some of the respondents were decided to suicide themselves. As the description of the study participants, the reasons they became worried are because of knowing the complexity and lifelong care and treatments of children with CP. As a result of having children with CP and knowing the realities of CP, all respondent mothers were faced extreme emotional disturbance and shocked for a longer time.

For instance one married respondent mother also narrated her initial reaction as follows:

"Before the birth of my child, I had no detail information in regards to the concepts of CP, but after the physician told me the realities, I feared out because, it was unexpected news. It took me a minimum of five days to accept the situation of my child. At that moment, I was really stressed and scared for everything. But after joining Cheshire

*service Ethiopia and observed other children with CP, I realized that, relatively my child is in a better circumstance when I see others."***MCP 3**

Similarly, another a 25 age married mother (MCP6) described her first reaction when she hears the result of her child's diagnosis as follows:

"After birth my child cannot suck properly. But, I didn't expect this condition… however after knowing the truth, I was shocked… I was very sad and distressed. I think the worst thing for a mother is the born of the child with developmental disability. Hence, I was so confused, how to care and handle my child…" **MCP6**

The researcher also discussed with study participants, what look like their experiences after recognizing the complexity and lifelong terms of caring such children with CP. After realizing the realities (for the permanent and incurability nature of their children's disability and the existences of unpredictable behavioral problem with the child); almost all respondent mothers were psychologically depressed. Unfortunately all of six respondent mothers who participated in group discussion were not ready to take care of their responsibilities.

As discussed with study participants, one respondent mother responded her first reaction as follows:

"Before gaining this child, I was not familiar with the facts of the concept of CP. I really suffered badly about having a child with CP. I was becomes very sad… not only for the care and treatments but for the endlessness of my child's disability. To be told a truth, at the beginning, I was worried only for the future life of my child but this was due to lack of knowledge about the difficulties of caring children with CP. I wasn't gave any consideration for the condition of the burden of caring such children. However, after coming across the complexity of car giving demands… I was detest myself and incredible to take care of my child. I felt sad inside especially when I look other non disabled children around my district; mainly when they were in walking, playing and running each other." **MFGD 2**

4.2.2. Perceived sign of depression and stress

All respondent mothers of children with CP were experienced suffering in depression for a longer time. The potential sign of symptoms which was observed on the participants are, unhappiness, loss of desire of food, blaming oneself, sleeplessness and leaving oneself from the social group (feeling of isolation or loneliness). Due to these problems, some of the respondents came to a decision for the act of suicidal but not put them to death. For instance, as noted by one respondent mother, her perceived depressions and stress was look like as follows; lack of appetite, wanted to live in an isolated room for a long period of time, self guilt/blaming oneself/, frustration, solicitude for her child's disability and disappointed for her child's future life.

She explained her experiences obviously in the following manner.

> *"When I think for the life of my child with CP, I locked myself inside of my bed room and cried for a long period of time… I complain the God, why he gave me such disable child and always blamed myself… Oh my God! It is shocking and I feel so bad. I want to live without food for several days because… I supposed myself as a valueless for this world! Frequently I like better to hide myself in my home. I didn't have any relationships with others even I didn't want to contact with my relatives… really It is extremely burden to have a child with CP because my child cannot talk at all. It is really demanding and stressful for mother".***MCP4**

Another respondent mother also explained her source of perceived depressive condition which comprised of; feelings of loneliness, hopelessness and being committed to suicide herself.

She described her previous and current experiences as regards to sign of depression in the next quoted paragraph:

> *"I have no any interaction with other and I don't like to involve in any social program either in marriage, birth date or other ceremony. Because I expected that, may some peoples has negative attitudes for me and for my child with CP. …I felt as friendless and anyone cannot need to form a friend with me, because of my child with CP. at the beginning, I remembered the reason why my husband had left me at hospital... because of the born of our child with CP. after that, I lost my hope and I didn't have a dream to live*

freely as other mother who haven't a child with CP. mostly nothing to fulfill my needs because life is nothing to me; I don't want to consider to lives in a good quality of life and life is meaningless for me; actually it is not worth living…" ***MCP2***

4.2.3. Source of depression and stress

As responded by all respondent mothers of children with CP, mainly they were lived in depressed situation as well as constant worry is usual for every respondent mother. Particularly, at the first phase of their children's life when they heard their children's diagnostic result, they were disheartened and disturbed for extensive period of their life. However, after joining Cheshire service Ethiopia for the purpose of their children to attain developmental rehabilitation service; most of them got opportunity to form friends with other mothers who have a child with CP and seek to manage their emotion as much as possible. In the other word, even after recovered from challenging condition, when they see other mothers of children without CP in their surrounding, they also develop feeling of guilty, depression and discouraged. Afterward, they were comprehended that, CP have different levels and when they look the profound level of CP (a child with CP those who are totally dependent on their mother); after comparing their children's disability level with other children who are at profound level, their fears and stress were reduced. Then, they realized that, they had made a fault in complaining of God. But still know some of the respondent mothers' (MCP2, MCP4 and MCP5) depression was not completely resolved.

In addition to this, when they see their children's typical age peer groups, they become depressed, anxious, stressed and acquire sleep disturbance. For instance, they believe that, if their children are free from CP; their children would walk and run around them as other typical peer groups and talk with them like other typical friends. As indicated by the respondent mothers, if their children born without CP; they would have a plan to put forward their children to school. Occasionally, they don't like to join their children with other typical friends because the child's friends without CP expected them as a very kid child or suppose as below their age level and said baby. Sometimes mothers of children with CP blame themselves, like, why God make this child disabled, when and how our child would eat independently as other children, when would our child walk equally as their peers. So, due to this, the majority of respondent mothers are worried, crying a lot, anxious, unhappy, upset and troubled.

For the evidence of these was the thought of one respondent mother, she was easily shocked and experienced unenthusiastic feeling when she look other children without CP those who are a peer of her child with CP.

She explained as follows:

> *''it is so difficult... one of a peer of my child with CP is my aunt's Child. I remember her child was born after three days of my child was born and when I go to my aunt's home and see her typical child, for the fact immediately I attack by strong headaches and emotionally disturbed. Afterward, I don't like to see again and I feel inferiority for my child because of his disability. Then, I was crying a lot… most of the time, I want to sit in my home, I don't like to move anywhere."* **Mcp5**

Another unemployed and a 3 years old child's mother also shared her experienced as follows:

> *"It is not easy to tell you what I experienced in bearing my mind... Please I don't like to remember it again… I have a great constant fear and sorrow in regards of looking other typical peer group of my child... actually; I was physically displayed sign of depression and distress because repeatedly people ask me 'why you are suffering in stress?' I talk to myself… if my child is nondisabled, he will walk and run as other his peer groups, he would eat independently, he would play foot ball with his nondisabled friends and I would also get some psychological freedom as other mothers of nondisabled children. Usually I blame and ask myself… Why God made my child disabled? Did I do a bad thing in my life? So, I was grieved a lot, I don't like to join my child with other typical children.''* **MCP 6**

As the account of the study participants, almost all mothers were experienced a great sense of fretfulness for the future life of their children with CP. e.g. concerned how their children would have social interaction with his/her peers and worried to organize their children to live in a wider society. They also worried for the future life of their children in regards to, after completing learning (after graduation); how their children could continue autonomous living or being employed.

For instance, as the description of a 36 years old respondent mother who suffered in stress and worried about the future life of her child thought that, she was disappointed for her child's future

life after she would die. She also stressed for the independent life of her child with cp. obviously she notified that, currently her health condition was not well and stressed out that, if she would die, there is no one who could accept her child and take care of her child's without doubt.

She shared and described her worries as follows:

> *"I am experienced sense of bothering for the future life of my child. …suffered in a great panic assault in regards to his autonomous living… actually I am not in a better life condition and I am not a healthy both physically and psychologically. I feared that, what would be happen to my child when I would die… how can he learn and live autonomously? I know the difficulties… even if when I sick, he sleep without eating dinner because he cannot eat alone. I know that, the only one who had fully accepted my child is me; this is due to the difficulty of caring such children. So, I worried about it and always I was afraid may my child would be illiterate, how can he live in this world independently. The fact that no one could not funds for his future life except me. Affording of food is also bothered me because, I haven't any work. For that reason, in addition to caring my child; I cannot gat sufficient time to engaged in any work as other. Generally, if I left this world; my child's future would be risky to live freely and he cannot get anyone who can treat him properly like me."* **MCP 7**

Similarly, another respondent mother also illustrated her worries for her child's future life in regarding his education, the possibility to retrieve from his disability and the potential to live independently. Furthermore, she also worried for the burden of care; she didn't save any money for his future life and it also adds stress for her life.

She narrated her worries for her child's future life as follows:

> *''I become anxious when I think for my child's future, I bothered, upset and ask myself forever... I think that, if he reaches a school age, how can he learn? I concerned for the sense of other students towards him? Moreover the time, I was worried and lost sleep for the incurability of my child's disability. Always I argued with myself, could my child's disability show progress in the future or keep on without change? Due to the condition of his disability, I was disappointed too much in regards to his independent living (future life). I know that, possibly may I will die; there is no anyone rather than God, who could*

treat my child. In view of the fact that, I spent my life in caring my child, accordingly there is no any legacy of money or property I have saved for his future life; due to this I was suffered a lot'' **MCP6**

One employed respondent mother who has a seven years old child also explained her practical experience as regards to the education of her child's with CP. she encountered greater challenges in searching school who can accept her child's with CP without doubt. As a result of luck of awareness among school administrators, inaccessibility of sufficient day care in school and educational facilities for those children with CP; a number of school were not voluntary to accept her child with CP. As the report of this respondent mother, the majority of schools were unable to meet the special educational needs of such children. Due to this, she was travel away far from her home; for searching and to find out the schools that have the capacity to support and accept her child's with CP without hesitation. But, even the special schools do not have sufficient facilities to support the child.

This respondent mother (MCP4) shared her practical experiences as follows:

"After my child arrived at school age, I was worried for his learning. My greatest joy was that he could finally attend school just as his peers, but that dream was unbelievable. I was discussed with several schools to enter him but I cannot found lovely response from school administrator. In fact, my child needs personal assistance to take care of him. One time I remember what one school principal told me, he said that 'we might accept your child but due to the nature of his disability he will disturb the others.' Then after, for the second time I searched other schools but I found comparable responses. Still, complained and hesitate to accept the child. However, one school said that 'those children need intensive care and treatment, so your child also acquire personal assistant but due to the shortage of budget we haven't enough guardian/assistant in the school. Hence, in order to accept your child you should have to assign one private guardian or you must be act as a Nanny in our school. In that case, I decided to work in the school as a nanny because of, the education of my child's. Actually, the school paid some money but I am not doing it for the purpose of getting money or I am not believed it as a means or sources of income." **MCP4**

As clarified by one respondent mother, currently she control her emotion and strong mentally but in the early years of her child's life, she were challenged to manage, direct and control herself.

As narrated by this respondent mother:

> *''It depends on your life situation....In my living environment; there is a great misconception for the causes of having children with CP. Some people understand that, as the result of misdemeanors activity committed by the child's families or due to wrong doing /sin/curse/. Due to this, at the earlier time, it is difficult to control my emotion and frequently upset by something. It was continued until my child became at the age of five years. But after accepting his disability, I was become emotionally and mentally strong. However, which does not mean that, I am totally free from any stress.''*

The result of the present study demonstrated that, some respondent mothers (MCP1, MCP3 and MCP7) were conflicted with their spouses because of having a child with CP. One respondent mother (MCP 2) also completely divorced; this was done because of her husband recognized their child's diagnostic result (as having CP). Beside to this, it was happened due to their husbands' inability to accept and ashamed by their child's disability. Loses of aspiration were evidently observed on the respondent mothers. Due to this, her husband was not capable to handle and manage their families properly. Through time**,** from seven (7) respondent mothers who participated in face to face interview, three (3) of them were observed some optimistic behavioral changes in their husbands, got appropriate feeling of affection for them and develop positive attitudinal changes towards their children's disability. The researcher realized that, there is an attitudinal difference among the spouse of mothers of children with CP.

As noted by one married respondent mother, after the birth of a child with CP, she was frequently quarreling with her husband. But, before the birth of her child with CP, she had a healthy relationship with her husband. Until now, her husband didn't worry for the child's life and embarrassed for the condition of the child's disability.

She narrated as follows:

> *"I know what we have before… my husband was enthusiastic and willingness to have a child but after our child was born as having CP; his sense of emotion was unfortunately*

changed. He was also embarrassed and discomfited regarding to the condition of the child. Moreover the time, he didn't want to give worship for us and doesn't respect me at all. He doesn't award any fund for our child's physiotherapy service, transportation service and for the child's unique needs. Mostly he thought as the child cannot recuperate or recover from her disability. In addition to this, he believed that, the problem is a fault that made by me. So, these situations eliminate our optimistic relationship and almost we are fighting each other…" (MCP 6)

As the description of one unemployed respondent mother, the reason of her divorce was due to the born of a child as having CP. Her husband left her, when she was arrived at hospital. Even though, at that moment she does not know where her husband is existed.

She described as follows:

"…During the born of our child and when he sure the child born with CP. …my husband left me and goes to his families. Until now, He has not seen his child and does not afford any money. Even his relatives do not assist me either morally or financially. For my expectation, they have not accepted the child's disability. The reason for that is, when I ask them for financial support; their responses were, 'it is the responsibility of the child's father so, please don't expect from us again' anyways it is so difficult and I don't like to remember again…" (**MCP 2**)

4.3. Care giving challenges faced by mothers of children with cerebral palsy

It has been reported by mothers of children with CP, caring a child with CP were overwhelmed for mother's emotion; with the consequences of sorrow, painful and grief. For the reality of missing hopes and dreams were obviously observed. As a result of the burden of caring such children with CP, the respondent mothers were experienced psychological distress, social isolation, physical health problem, sleeplessness and marital problems. As narrated by some respondent mothers, during night they cannot get enough sleep because their children cry a lot. They were psychologically depressed because of lack of support and limitation of assistance from their families. So, these psychological depressions add the burdens of care giving demands. Most of the participant mothers were felt that, people were ignored them and would not accept their children because of their children's disability. Due to

this, usually they blame themselves and ashamed by their children with CP. Except two, the remaining four respondent mothers explained that, they experienced greater shoulder and back pain problem which was resulted from carrying up and lifting of their children, such as from home to physiotherapy service and the difficulties become high, particularly, when they walks long distances.

Furthermore, the most common challenges that reported by all respondent mothers were social isolation. Actually, after having children with CP their social participation was reduced and in some case totally eliminated. Therefore, they cannot interact with their neighbors, friends and community in any ceremonies, such as in wedding, holidays, funeral etc. In most cases, the care giving roles was also restricted and makes them to stay at home. In view of that, they could not visit their relatives and cannot participate in any social activities equally as other mothers of typical children. As reported by the study participants, they unanimously agreed that, financial burdens are also the main challenges in regards to caring their children with CP. It was approved by all respondent mothers that, money played a vital role in the upbringing of the children's unique needs. As a result of caring their children with CP, they lost their own works, missed a lot of working opportunities and restricted to engage in gainful employment. Due to this, they lost their hopes, dreams and self confidences to live independently.

As indicated by one respondent mother (MCP3), much of her time is taken up with care giving her child with CP and she has little or no social interaction with others. Even she was not freely interacts with her neighbors and relatives. As the clarification of such mother, caring children with CP limit mother's interaction and mainly she kept out herself from any social participation. In addition to the task of caring her child with CP, essentially she was excluded herself and stayed at home because of the negative attitudes and lack of awareness for the causes of CP that reflected by the societies. As her understanding, her qualities of life are already reduced; this was due to the care giving burden. She narrated that, currently she was living in a deprived and uncomfortable lifestyle.

She narrated her experiences in the following manner:

"For the fact I don't like to have any relation with other... essentially, I don't have any social interaction in my surrounding either with my relatives or neighbors because of the care giving demands… actually, I cannot have a good feeling to interrelate with others. I was afraid that, may someone laugh mockery, disdain and ridicule by my child. Before having children with CP, I have a good relationships with my friends but I remember one day my colleague derisively laugh and make sarcasm by my child and then noticeably told me, 'the reason why you acquire a child with CP is because of your sin, curse and I believe that it a is punishment from the God.' after that day, I was totally dropout my interaction from any person. I know my interaction with my husband was also decreased because of the burden of care giving role of my child with Cp. I know that, this care giving burden really makes a marital problem in my life. Currently I haven't lovely marriage and mainly we were hassle each other. When I realized these care giving burden in regards to the child's age; really it was probably worse at the present time of my child's age and difficult to care when the child grow up. In addition to the age of the child, the severity of the child's disability also makes the care giving burden to be complicated. I believe that, really I don't have quality of live and I'm living in painful situation." **MCP3**

Another one divorced respondent mothers (MCP 2) also expressed her experience of socially isolated from friends and community members. This was because of the result of being ashamed for the condition of her child. She illustrated her thoughts as follows:

"Most of the time, I locked the door on myself and stay indoor with my child because I was extremely embarrassed, may peoples laughed or blamed me due to my child's disability. I am experienced feeling of guilty because of my personal expectation for the negative attitudes of peoples. Due to this, I cannot go to any ceremony like weeding, holidays, or birthday. I haven't any social relation with others and most of the community member cannot assist me. Even my husband's family doesn't help and visit me. As the result of less interaction with others and feeling of disgracing for the condition of my child's disability; I am the merely care taker of my child and it was difficult to fulfill my child's needs. So, I am always carrying my child even when I was travelled in the bus. I remembered once when I goes to rehabilitation center (Cheshire

service Ethiopia); during that, my child was not control his neck and his neck was not in a normal position because of his disability. Then, one young woman who existed in the bus look down my child with a great ignorance and she said that, 'is he autistic child? Afterward I was become very angry and immediately seize and grip her throat and told her even though my child is autism; what worried you. Then I cry a lot… I don't like to remember that moment…" **MCP2**

As the explanation of two respondent mothers (MCP1 and MCP4), it is hard to obtain freedom or the state of being relaxed on holidays because of the complication that associated with the condition of their child.

As narrated by MCP1:

"Is nothing to me to go away on a holiday because, my intellect is already stressed for my child's future life and passing holidays with other peoples is absolutely frightened for me. It's really uncomfortable and embarrassed to find something which provides accommodation for us. So those kinds of things are hard to find relaxation and good state of mind on holidays. Almost all time, I don't like to participate and celebrate in any holiday ceremonies with others. Even the family members or relative's birth day cannot give pleasure and totally unsafe for me and for my child". **MCP1**

Another respondent mother (**MCP4**) also described her feeling for the complicatedness of caring such children with CP as follows:

"Caring of children with CP is very difficult because the care and treatments of such children are complicated and not trouble-free as typical children. It is not easy to understand the child's behavior immediately because they have flexible behavior. In most cases my child has a behavior of whining, crying, unable to explain his feeling in spoken form; this add up the burden on caring of my child. Rather than crying, he does not clarify his feeling obviously as others typical children. Sometimes, when I gave my breast, he detests sucking. More or less, it is difficult to understand my child's emotion as well; which makes the care giving challenges to be hard and worst. To be told honestly my child cannot eat independently at all; so, always I feed him. Currently he is a seven

years old child but, rather than crawling he cannot walk and standup independently. So, I carried him even doing any works at home. He cannot toileting properly as his non disabled peers; as a result, I am the only person who should change his diaper. Always he cries a lot, due to this, I haven't got enough sleep to take rest at night. In general caring children with cerebral palsy are hardship, make restless and busy, eradicate psychological wellbeing, agony and painful. I believe that my back pain problems are the result of the burden of carrying my child with CP for a longer time." **MCP4**

From the finding of the study the researcher also analyzed that, except one mother (MCP4), all respondent mothers of children with CP were unemployed; this was resulted from the case of having children with CP. From seven respondent mothers who participated in face to face interview, before the born of their children as having CP; three of them (MCP2, MCP3 and MCP7) were employed. But after their children born with CP; they lost their previous works and lost further work opportunities. This was due to the care giving demands of their children with CP. As the description of two respondent mothers (MCP5 and MCP6), they got several work opportunities but missed due to the complexity of caring their children with CP. In addition to this, those mothers were worried to assign a home guardian because it is difficult, may the guardian could not achieve her responsibilities properly or incapable to give appropriate care for the child; really it makes them to be highly suffered in constant worry. Another respondent mother (MCP1) was also confused and afraid to apply in some private institution. Determined from the fact that, due to her personal reaction of ashamed by her child's disability; she fears the organizational executive administrator, they might be involuntary to accept and allow her to engaged in their business because they might believe she could not effectively achieved the given responsibilities as other employees.

One unemployed mother (MCP7) described and shared her lack of employment experience as follows:

"Before the birth of my child, I was civil servant and worked in governmental office as a secretary. When I was pregnant, I was taken a four month birth rest. But unfortunately, my child has born with CP. After lasting my four month birth rest, I was expected to continue and return to my previous occupation like other mother. Except for

only two days I can't to keep on my work... Even for those two days, I was sent my child to my grandmother. However due to the difficultness of caring such children; my grandmother cannot handle my child rather than two days. Then after, completely I decided to drop out my jobs. In the other word, I was not voluntary to give my child for other individual like guardian because; I cannot feel comfort when my child separated from me. Still now, I haven't any work rather than caring my child with CP but sometimes I want to create and run my business like distributing roasted grain of nut for kiosk and supermarkets but how? Is difficult to do so… actually I believed that, I cannot live a standardized quality of life and I am not fulfill my needs and worried for my future life. …really I am wasting my adult age and my life could be simply dissipated…" **MCP7**

One unemployed mother (MCP3) narrated her work experiences as follows:

"In the past or before the birth of my child with CP, I was employed and worked at private restaurant as a waiter and sometimes I was act as an assistance cooker. But it was failed out because of the birth of my child as having CP. after the birth of my child, I was not returned to my earlier occupation and I cannot involved in other job. For the fact, it is really difficult to involve in any job without assistant who can handle and care my child with CP. Subsequently, my daily income was become low, then attempt to apply in several private and governmental organization to raise financial assistance. But, due to lack of awareness for the challenges of caring such children, they cannot afford any funds because they assumed that my child cannot fulfill the eligibility criteria for receiving financial aids." **MCP3**

Almost all respondent mothers who participated in the present study have the experience of sorrow by the time consuming, overwhelming and lifelong nature of caring such children with CP. All seven respondent mothers who participated in face to face interview were agreed unanimously on the difficultness of caring such children with CP. Particularly, the difficulties were become hard care those children who have sever impairment and who have additional disability. In addition to long term care and treatments, the lifelong dependence of such children with their parents; especially, for mothers create hopelessness for the rest of their lives.

One respondent mother (MCP1) shared and described her sense of emotion as follows:

> *"In fact, the nature of nurturing such children is extremely time consuming, they needs a never ending care, boredom and profoundly living in a feeble manner. In fact, I spent a higher range of time per day with him. I supposed that, this will be a lifelong role for me ...and probably for the rest of his life my child will be permanently dependent with me. I remember that, during diagnosis the doctor told me for the incurability of my child's disability. These increase to loss my future life aspiration…"* **MCP1**

4.4. Mothers interpersonal relationship with their children with cerebral palsy

With the evidence of the study finding, there is a healthy, protected and positive mother-child relationship. All respondent mothers who participated in the present study have strong positive physical attachment with their young children with CP because of their natural love. Additionally they were optimistic to play and look after their babies every day. But this does not mean that, not all respondent mothers have comparable relationships with their children with CP. Actually, every mother differs in their belief and upbringing of their children. They believed that, a great part of a mother's job at home could be accountable for the physical and psychological well-being of their children. Therefore, all respondent mothers make everything better and fulfill the basic necessities of their children as much as possible.

Of course the researcher also recognizes the following mother child interaction. All of the respondent mothers displayed appropriate facial expression and hold their children properly, adjusting a safe sleeping environment, in the leisure time they tells story, fairy tells, puzzle and jocks through expressing amusement and do several recreational activities like child play for their children, there is a good interaction at mealtimes in feeding their children, in general they have a better outlook for their children and attempt to understand their child's unique way of communication system (i.e. gesture, eye pointing, body movement etc).

As the report of one respondent mother, she has a strong relationships with her child with CP. she spent more time with her child through take care of various skills including

communication, social, and reinforcing positive behavior of the child. She also makes and eats meal with her child whenever possible. She has never lowered her child status and ignores him.

She explained her interpersonal interaction with her child as follows:

> *"Really I have exceptional love for my child and I spent more time in caring him. I am very happy and feel comfort when I spend my luxury time with him. I don't want to my child to feel unhappiness, discomfort, to be cry, and to be angry. I treat him properly as much as possible. I'll never show improper facial expression. Rather than feeling safe, I am not change his diaper when he is crying. We always spend our time freely, in joyful and pleasurable manner. Honestly, I believe that, my child is really my life; I cannot live without him. I spent my time in feeding with him, practicing communication skill, appreciate him to strengthening his behavior, encouraging and acknowledge with words of his positive behavior. Sometimes, I asked some simple puzzles and told story for my child. He also wants to watch some television program with me like, (ye-Ethiopia lejoch program and National geography). Usually, I play with him as a kid or act as his peers"* **MCP 5**

Another mother also illustrated her optimistic interpersonal relationships with her child with CP. She has unique love for her child and always wants to spend her leisure time with him. In this moment she wants to born additional children but she afraid to add other children because she felt that, due to burden of caring, she might become busy and may be her child with CP couldn't find sufficient treatment. Due to this, she afraid may her child will turn into be abused.

She described her day to day interaction with her child as follows;

> *"In fact, I loved him greater than my life. Really it is difficult to live without him. I don't worry for my present life… always I am considering and following for his growing up… forever the time, I was spent my full time with my child. At the present time, I want to born another child but how… in addition to the*

burden of caring such children with CP; I'm afraid may I left him and he may turn to be abused." **MCP 6**

Another respondent mother who worked at in her child's school as a nanny/guardian also expressed her positive relationships with her child and she worked in the school because she wants to look her child to learn equally as his non disabled peers.

She expressed her thoughts as follows:

"Actually I have a good attachment with my child. I love my child a lot... I don't know how I can express my love… I don't want to observe my child to live in a depressed condition and I am not disappointed to take care of my child. The reason why I am worked in my child's school was because, my child should equally attend his learning as his non disabled peers and my child to develop confidence, when he learn with others and I also afraid, may my child could be illiterate. Usually I teach my child how can interact with his classmates as much as possible." **MCP 4**

From the findings of the study, the researcher found that, most of the respondent mothers were not trouble to communicate with their children with CP. As narrated by such respondent mothers, their children with CP have not hearing problem, but have speech difficulty. So, mainly those children use their natural mode of communication. For instance, mainly their children express their feeling through facial expression, gesture, eye-pointing, body movement (nodding of head), crying, whining, chuckling and murmuring. Although, due to lack of sufficient vocabulary and limitations in children's communicative competence; those children cannot provide explicit information and may necessitate communication followers seeking clarification to continue the conversation. Therefore, their mothers usually clarified, repeated and revised their original message and usually they used very simple sentences to practice their children.

One respondent mother confirmed that, she were not trouble to communicate and understand her child's feeling, desires and either happy or not. Even if a child might have a health problem; she can understand immediately by looking his face.

She demonstrated her mode of communication with her child as follows:

> *"I haven't any problem to understand my child's sense of emotion even he have some health problem. In point of fact, he can hear all the incoming sounds and comprehend correctly what the other said in spoken forms. After hearing the message what I told him; then after he will express his feeling through eye pointing, nodding, or by other body movement. For instance, when I want to feed my child, first I would like to ask his desires/choice/ by bringing food with alternatives; then he will show his choices by pointing his eye. When I ask him by calling his name and 'do you want food please?' if he like and want to eat; he will nod his head but, if the selected food is not his choice; he will turn his head sides to side."* **MCP 7**

Another respondent mother (MCP 3) also narrated how to communicate with her children with CP as follows:

> *"I have a positive relationship with my child in our everyday life and I comprehend his idea as well as his attention instantaneously. Essentially, he has a speech problem but In fact he can hear and understand my ideas properly and gives respond for my question. But the mode of communication is not identical with other typical children. If he wants to drink water or have feeling of thirst, he gives more consideration in looking water or makes his tongue out of his mouth. Then I comprehend his feeling easily but people ask me like, why your child turned out his tongue? During that, when I give water, he could drink and stop salivation. Similarly, if he wants to go out of the home, he will show his feeling by representing his finger outside the home. If he wants to toileting or want to the diaper to be changed, he would quickly breathe. He also expresses his grief through crying or murmuring. After that, When I told him to stop his lamination; he will completely discontinue and hesitate weeping. If he wants to stand up, he will look upward and sounded unhealthy voices and then I will carry him."* **MCP 3**

As the account of one respondent mother (MCP5), she has an immediate eye contact with her child and she can understand her child's needs and feeling. Beside to this, the reason why she has immediate eye contacts with her child because, she worried that, may her child could be failed down and acquires further impairment. In addition to this, she also has a realistic biological love

for her child. As her explanation, she looked after her child with pleasure and has a superior quality of natal bond with her child's with CP.

She illustrated her attachment with her child as follows:

> *"I have a great value for my child and always understand his reaction at all. My desire was to look my child to be in a lovely lifestyle in his everyday life. I saw him in every moment with eagerness… even when I was doing something my eyes cannot leave him because I don't like to look him supplementary injuries in his body. I suppose that I have a wonderful attachment with my child."* **MCP5**

The results of group discussion demonstrated that, almost all respondent mothers who participated in the FGD had a fantastic relationship with their children with Cp. Many of the participants who have participated in group discussion can adapt the situation to interact in the right way with their children with Cp and comprehend their children's facial expression easily. Because of the severity level of their child's disability; some of the participants were trouble to understand their children's cue and challenged to communicate and interact freely. In addition to this, due to motor impairments such children were trouble to play independently and needs assistance to assist them in physical activities. In most cases, during communication, such respondent mothers dominate the conversation because to encouraging and stimulating their children purposely to generate certain target behaviors. These strategies helped them to improve their children's communication skills as well as to have a full range of pleasurable interaction skills with others. They narrated that, they have an intimate and closer relationship with their children because of their worries may their children acquire further disability due to the consequences of their laissez-faire follow-up. As result of this, they have an immediate eye contact to keep them from any harm.

As discussed with study participants in focus group discussion, one respondent mother narrated her lived experiences in regards to her relationships with her child with CP as follows:

> *"I have a friendly relationship with my child. I understand his sense of emotion easily. He cannot exchange his ideas in verbal communication. Even at the present time, he show various sort of pause and hesitation during spoken forms of communication. But,*

he can express his feeling by a means of facial expression and through the indication of body movement. So, we can easily exchange our ideas without doubt. Moreover the time, I was spend my leisure time with him through playing with him, telling funny story, goes to out of the home and singing a religious song of praise (anthem) etc. In addition to this, always I had kept my child from any harm and follow him whenever he played with oneself." **MFGD3**

4.5. Possible coping mechanisms employed by mothers of children with CP

One of the themes that were emerged in the present study is the coping mechanisms that employed by mothers of children with CP. the respondent mothers were employed different coping strategies, to adapt, manage and retrieved from stressful and demanding condition. The most common strategies that were employed by respondent mothers are accepting the child's disability, being of patience or regulating once emotion, religious coping/faith healing/ or through spiritual practices, and receiving social support from friends, families, community members and concerned professionals who worked with children with CP. As noted by all respondent mothers who participated in the present study, the most probably important mechanisms that can assist them to recover from stress are being of patience. But which does not mean that, the others coping mechanisms are not significant. In addition to this, commonly all of the respondent mothers were utilize developmental physiotherapy service for their children to retrieve from their disabilities. In this section the sub heading that could be presents are the common coping mechanisms that employed by the respondent mothers; i.e. accepting the child's disability, being of patience or regulating once emotion, religious coping/faith healing/ or through spiritual practices, and receiving social support.

4.5. 1. Religious coping /faith-healing/ or spiritual practices

All respondent mothers reported that, their personal faith was assisted them to cope from stress. Since, in addition to its positive consequence; it is easier to apply any time wherever possible. By applying this coping mechanism, the respondents also being beneficial to manage and adapt the challenges concerning to caring their children with CP. Furthermore, some respondent mothers were also believed that, they had been holy in acquiring such children and selected for the task of being mothers of such children and they had been given with the intention of this task with a

hidden reason. As the report of some respondent mothers, they expected that, their child's disability was not a fault of God; but rather than making mistake it was to select them as his beloved one.

One respondent mother described her coping experiences as follows:

> *"I believe that the God has given this task of caring my child with CP for me with a secret reason. Essentially, I never have any consideration/dreams/ to acquire a child with CP and I had never had a dream of being a mother of such child. I suppose, it is blessing and good approval for me. I believe that, I'm a chosen one. The God had chosen me because of a reason to check my strength in faith of him and to provide a heaven. Sometimes, I told myself and believe that, the God never make any mistakes and my child being of disable is not a fault of God. I know God is with me, I hope one day he will return my child to a normal condition. In the power of God, my child will retrieve from his disability. Whenever the time, I am going church to pray and say thank for my God. After staying several time in place of praying; really I had came back with a usual or normal condition and got a hopes due to staying in praying Gods."* **MCP 5**

As noted by one respondent mother, she also got an emotional support when she follow and frequently praying and talk about her heartfelt feeling for the issue of her child's disability to god.

She described her experiences as follows:

> *"For the truth, I was got a great deal of emotional strength from keeping myself at place of praying. Most of the time, I am going to church to pray and express my internal worries… after requesting and expressing my deepest fear; I got a larger amount of happiness and turned to standard condition. …and pray about it for a long period of time. After praying and blessing a God about the issue... then turn back to home with a full of happiness… for the fact with a great happiness."* **MCP 4**

Almost all respondent mothers used different spiritual practices or traditional healing for their children with CP to recover from their disability. However, the practice of these traditional healings are varied among mothers depends on their religion. For example, for Orthodox mother

they were use holly water (Tsebel), ashes like substance Qiba Qidus (eminet) etc. A Muslim mother also uses reading Quran, making Duaa by sheiks, Nezir (Silet), etc. They reported that, after employing such traditional healer they become satisfied and acquire psychological freedom. Still now they are used these spiritual practices for their children with cerebral palsy.

As the account of one respondent Orthodox mother she used holy water and Qiba Qidus /emenet/ as a coping mechanisms to deal with stressful situation and apply it even on the child's face for seven repeated days and she was believe that in addition to physiotherapy, the holy water was help her and saw some progress on her child.

She described her experiences as follows:

> *"After my child screened as having cerebral palsy, my first decision was to go to St. Marry holy water which was found around my home. I was found it as a best mediator of stress because before utilizing it, I am living in constant worry but now really it was slightly solved. In addition to me, I was also applying it my child. My child was used drink and showered by holy water for seven days continuously. In addition to using holy water, I was also put ash like substance (Qiba Qidus or emenet) on my child's face for a several time. Really it helps me and observes a great progress on my child life. Due to observing such improvement in my child's life; really I was recovered from stress"* **MCP 7**

Likewise, one respondent Muslim mother also shared her experience in utilizing deep praying/making Duaa/, Nezir/Silet/ and experienced in reading religious texts book (Quran) by sheiks and by herself. As her assumption, she was observed a sort of changes in her child's physique.

She explained her coping experiences as follows:

> *"After realizing my child as having CP; I was seek to find a lots of strategies to deal with stress such as, praying Allah (making of Duaa), frequently reading religious text book (holy Quran) etc. I am sure that, I was found a lots of benefit from those traditional hillier. To be honest, the above mentioned coping mechanisms are usual in our surrounding especially in Islamic religion. After applying those techniques; I also get psychological well-being and happiness for various days but not completely recovered from stress"* **MCP1**

4.5.2. Receiving social support

As reported by study participants, receiving social support and encouragement helped them to get well from stress. Acquiring social support increases their potential to cope with stressful situation and to have healthy mind. Due to receiving social supports from friends, families, and community members; they have also understand how the societies have a positive attitudes towards them. In the other word, the encouragement which provided by neighborhood or other professionals enhance the positive attitudes of those mothers of children with CP for the societies. On the other hand, in some cases, some people provide financial aids with giving their personal wrong impression as of being recipient person comprises a psychologically distress.

She narrated her experiences as follows:

> *"Really receiving social support assisted me and I was got several benefits from my friends and community. Once upon a time, when I carry my son to school; one elder father gave me a lift then asks me 'why you carry this older child? Sorry! Still you are carrying your child even in the car… really sorry. If you know that, you make a fault in caring your child…' afterward I told the fact and the real condition of my child's disability and then ask me to apologies for the happening of his wrong impression. At the end, what makes me shocked was, he gave five birr and said 'my mother told me to give such money who look like her' in that moment, immediately I have turned out to be angry, sorrow… his thoughts disheartened me. Actually, I understand him, he want to support me but he does not consider how his speech can disturb me. Really I know that, such like words and dialogue can lowers the mother's dignity. But unfortunately, many people cannot recognize how it can limit mother's social interaction, disturb her emotion, and upset by their speech"* **MCP 4**

The response of another mother was also expressed as follows:

> *"I have received support from my friends, families and professionals. For instances, I was remember at the early years of my child's life; my child was attained physiotherapy service in private sector. Once due to lack of money, I hadn't a service fee then told for the owner I can't continue the physiotherapy service because of money. Then the owner financially assisted me and provides two thousand (2000) Ethiopian birr to keep on the*

service. In addition to his economical support, ideally he also encouraged me to have self confidence for the recovery of my child's disability. Subsequently, he recommended me 'the God would check his beloved individual's strength, so, you should have to develop a positive perception for acquiring such child. I also have a child with CP but after taking physiotherapy service continuously for six years, he can tried to stand up and walk independently with his legs.' In fact, at that time I got a higher effort and retrieved from stress" **MCP 2**

As the description of respondent mothers in the discussion session, they were used different coping mechanisms to adapt the demanding situation, to control their emotion and to recover from stress. For instance, the most common coping strategies that was raised in the discussion are as follows, listening music, watching film, reading religious texts (Quran or Bible), drinking holy water (Zemzem water), praying (making Duaa) at praying chapels, regulating once emotion (being of patience), forming optimistic relationship with others, getting encouragement and social support from others. On the other hand, they were also employed some negative coping mechanisms like, crying, isolation or withdrawal from the social groups and keeping silent or unresponsiveness. As discussed with study participant mothers, way of utilizing such coping mechanisms were vary among mothers. But after employing those coping strategies, their stress was reduced and got a potential to regulate their emotion easily. In addition to this, they obtain a possible effort to assist and take care of their children properly.

From the group participant, one younger mother illustrated her personal coping experiences as follows:

"I am advantageous in employing different coping strategies. But moreover the time, I watched film and listen softy music and sometimes, I am going to a far distance from my home within oneself. To be told in honest, after seeking this strategies, the sense of frustration, depression and stress were instantaneously changed and acquire being of happiness. Besides to this, occasionally I want to lock the door on myself and cry a lot, I don't like to join even with my relatives…" **MFGD1**

As discussed with study participants who participated in the focus group discussion, another respondent mother also point out her experiences of stress adaptation mechanisms as follows:

"I remember that, before using some significant coping mechanisms, due this heartbreaking new I was very sad… due to this, once upon a time, I was decided to suicide myself… but after advised by my earlier best friends, I was recovered from that constant worry and gain a power to accept my child's disability. Then after, came to a decision to regulate my sense of emotion and to being patience. Really peers encouragements have a vital role in coping from stress and to live in a good quality. Subsequently, the assumption of nothing to live in this world was eradicated. I was attempt to employed different coping mechanisms like, drinking and showering holy water, spending at a place of worship with my child. I was stayed at church for praying and asking gods to retrieve my child from his disability. In fact, after following and practicing the above techniques, I was observed numerous changes on my child physique and I also offer potentials to control my sense of emotion which comprised to look forward for my future life."
MFGD 6

4.5. 3. Emotion regulation/ Patience/

As discussed with study participants, unanimously all of the respondent mothers were agreed and confirmed for the significances of regulating once emotion to cop from stress. As their explanation, after developing to regulate once emotion to tolerate their children's disability; they got a chance to recover from stress effectively, well again to administer the stressful situation and obtain psychological strength to take care of their responsibility towards caring their children with CP. As the description of such respondent mothers, when they had become more patience for the condition of their child; in parallel, they were able to have a good aspiration, emotional stability and to adapt the stressful events. The researcher also asked them why they choose to be patience and they responded that, the result of stress is mental illness, push to fight with other, and also if a one who live with patience, one day the god also retrieved his/her disabilities.

One respondent mother described as follows:

> *"I believe for being of patience because I got a lot of benefit after that, my endurance becomes well-built. When my child was born with cerebral palsy… during that, for sure I was enormously anxious… particularly when I know the permanent nature the events; to tell the truth I was turned to unconscious... In addition to this, inevitably I was nervous and acquire a greater amount of demands for the lifelong care and treatments of my*

child's with CP. after a several time, I was initiated to being a patience because it is easier way to adapt and resolve the reaction self guilt. Following of such mechanisms make my life to be powerful in order to tolerate the condition of my child's disability. In fact, this strategy assisted me to alleviate the stressful situation. I would like to emphasis and recommended for other mothers of children with CP to practice this strategies. I am sure that it can assist them to control their sense of personal emotion." **MCP 3**

Another respondent mother also shared her real life experiences regarding to regulating her emotion. She explained her experiences as follows:

"In early years of my child's life it is difficult to regulate my emotion. Actually being of patience was helped me to accept my child's disability. After developing a positive internal motive to accept my child's disability; I was get back from stress easily and advantageous by practicing such coping mechanisms. The reason why I want to be patience was because if you tolerate the present life challenges; you will find an extreme psychological wellbeing. Essentially, I believe that, everything will come with opportunities.'' **MCP 6**

4.5. 4. Accepting the child's disability

One of the coping mechanisms that employed by the study participants to regulate their stress towards to take care of care giving responsibilities and to recover from stress was accepting their child's disability. As the explanation of study participants, in the early period of their children's age; they had been challenged to accept their children's disability but after through time, they came to a decision to accept their child's disability without doubt. As narrated by such respondent mothers, after accepting their children's disability; their care giving roles became easier and their state of sorrow was slightly decreased.

Correspondingly, one of the respondent mothers was also reported her experiences to accept her child's disability and how can challenged in the early years of her child's age but after accepting her child's disability; she got internal strength to regulate her emotion and less trouble to cope from stress. In addition to accepting their children's disability, acquired social support was also assist her and significant coping mechanism in order to adapt and control the challenging situation. She narrated her mode of coping style as follows:

"I believed for the importance of acceptance… at the beginning frequently I attempted to accept my child's disability but difficult at early age… I accepted my child's disability after a long times. After understanding the positive consequences of accepting the child's disability; one day just I told myself to accept my child's disability without hesitation. Subsequently, I have to decide to accept the realities. After accepting my child's disability; really it makes me powerful to cope from stress. I was become free from stress and the problems that were come to mind to live with my child are completely eliminated. …afterward I don't mind for my child's disability. Moreover, because of my personal approach, other people also show feeling of affection for my child with CP. I also clarify my pleasures and appreciation for every person who does not neglect my child." **MCP 6**

Another respondent mother also described her consideration to accept her child's disability as follows. But still now her husband does not accept the condition of their child's disability.

She noted her experiences as follows:

"Basically it is difficult to accept…but I haven't any chance… there is no other possibility rather than accepting the child's disability. Hence, when I joined to Cheshire service Ethiopia and receiving skill training as regards to caring such children with CP. I remember ways of coping from stress was a part of training and the trainer obviously and repeatedly expressed for the significance of accepting the child's disability as follows; 'next to having such children, accepting their disability was mandatory for care taker, especially for mother.' Additionally, the physiotherapist and center coordinator was also recommended us to accept my child's disability without hesitation. Afterward, I was attempting to follow and apply this approach. Really, after applying such strategies; I turned to usual and standard condition. Really the counseling service which has done by rehabilitation physiotherapy professionals were helped me to accept my child's disability. But my husband still knows did not accept the child's disability but I don't know the reason. Always he keeps quiet and unlike to talk about the issue of our child's condition…" **MCP1**

CHAPTER FIVE

DISCUSSION

Introduction

The main purpose of the present study is to explore the psychosocial challenges encountered by mothers having children with CP. In this section, the major findings of the present study are evidently discussed and prospected with the findings of other previous research. In this regard, the current study is discussed and logically arranged in regards to leading research questions. Accordingly, the researcher examined and discussed on the major thematic areas of the study, which includes; mothers' psychological challenges in regards to having children with CP, the care giving Challenges faced by mothers', the mothers interpersonal relationship with their children with CP and the possible coping mechanisms that were employed by mothers are sequentially discussed and arranged.

5.1. The psychological challenges faced by mothers of children with CP.

5.1.1. Mother's initial reaction

In order to provide a quality of care for such children with cerebral palsy, the mother's psychological/emotional states should be existed in a comfortable manner and develop feeling of cheeriness; because, it plays a vital role for the positive outcome on behalf of the child's life.

The results of the present study demonstrated that, mothers of children with CP faced a lot of psychological challenges which comprised of depression, sleep disturbance, constant worry, feeling of inferiority, ashamed by their children's disability, self guilt/blaming oneself and feeling of suicidal. Mainly mothers are unable to accept the diagnostic results of their children and they lost hope to look forwards of this life and being a parent (Huang et al., 2010; Whittingham et al., 2013). In parallel to this, several studies were conducted in different countries and confirmed that, those mothers of children with CP were experienced and faced higher psychological distress because of having children with CP e.g. (Brehaut et al., 2004; Seltzer et al., 1995; Bumin et al., 2008; Singogo, Mweshi and Rhoda 2015; Davis et al., 2010; Sajedi et al., in 2010; Marika, 1999).

Similarly, previous research findings also confirmed that, mothers of children with CP often experienced higher level of depression. For instance, as stated by (Barlow, Cullen, & Cheshire, 2006; Britner, Morog, Pianta, & Marvin, 2003), parents of children with CP have higher levels of psychosocial distress compared with parents of children without a disability.

In the present study as explained by the respondent mothers, they were shocked when the physician told the permanent and incurability nature of their children's disability. If a child is screened out as having CP, being of grief and worry are a normal reaction for most mothers' of such children with CP. Correspondingly, it is also matched with previous research finding which was carried out by (Ozsenol et al, 2003), confirmed that, Shocking is usually one of the first reactions of mothers and it is common due to unexpected results of their child's diagnosis, but mainly mothers are explained their state of being shocking through crying, lack of response and feeling of helplessness.

Before the birth of their children with CP, almost all respondent mothers had not had awareness concerning to the real information of CP. In parallel with the present study, earlier studies have also revealed that (Huang, Killett & St John, 2010) as cited in (Singog, 2012), the first reactions may vary among mothers, but often they experience periods of panic, anxiety, helplessness at which point they face overwhelming depression, apathy and bitterness. In contrast with the current study, in some instances, a parent or caregiver may visualize as regards to killing the child by reason of unpredictable future of their children with CP… (Abidoglu & Gumuscu, 2007). In the present study, rather than appalling and sadness by the condition, from the respondent mothers no one cannot wants to kill their children with CP but, for most mothers, at the early age it is crushing, sorrow and heartbreaking in the reality of lost hopes and dreams becomes obvious (Huang, Kellett & St John, 2009).

5.1.2. Perceived sign of depression and stress

In the present study, after realizing the reality, those mothers of children with CP initially suffered in depression and shocking. In general the major sign of depression and stress are unresponsiveness, crying, blaming oneself, withdrawal, hopelessness and loneliness. In parallel with the finding of the present study previous study also carried out by (Ozsenol et al, 2003) supported this and confirmed that, mainly mothers are explained their state of being shocking

through crying, lack of response and feeling of helplessness. Beside to this, due to heartbreaking condition of their child's life, some mothers can lose their hopes and dreams (Huang, Kellett & St John, 2009). Similarly, Parents have feelings of sorrow and unhappiness because of realizing their children's diagnostic result (Whittingham et al., 2013). As the report of the respondent mother, mainly they want to stay at home alone, cry and guilt herself.

In some cases as the account of the study participants, due to suffering in constant worry, they were confused even how to handle their children and take care of their responsibility. This was corresponded and supported by previous studies, for instance earlier research conducted by (Brehaut et al., 2004) confirmed that, mothers of children with CP are confused how to caring their children with CP. Likewise, a study carried out by (Marika, 1999), the result revealed that, parents, especially mothers of children with disability, have significantly more negative emotional states and also significantly more depressive and warning sign are easily observed.

The result of the present study demonstrated that, mothers of children with CP show feeling of inferiority because of the attitudes and responses made by the community members. Due to this, mothers' social interactions were limited and decide to withdrawal themselves from the social groups. They were felts as friendless and anyone cannot need to form a friend with them, due to this, they supposed that, living alone as well as staying at home is better than social interaction. These findings are comparable to the prior studies done by (Nimbalkar and his colleague, 2014) confirmed that, the primary caregivers (mothers) social participation is mainly little and restricted, because the questions which raised by relatives, friends and other community make them to feel inferior and uncomfortable to engaged in social event. In the same way, the finding of the study which was conducted by (Singogo, Mweshi and Rhoda, 2015), confirmed that, mothers of children with CP feels socially isolated due to lack of support from the family, community members and health care providers. Mothers are often experience financial strain, stigmatization made by others; lack of access to services, and lack of information in regards to CP are sources of depression (Davis et al., 2009; Donald et al., 2014; Thrush & Hyder, 2014)

5.1.3. Source of depression and stress

The finding of the present study revealed that, mainly seeing and bearing in mind of other typical peer groups of their children with CP, considering the future life of their children with CP, worrying for the education of their children, negative responses and some misconception that made by the community members are a common sources of depression and stress. The mothers feeling for the lifelong care and treatments of their children with CP also are the major sources of depression and stress which were obviously expressed by the study participants. In line with this, due to cultural beliefs, society's perceptions are for the birth of a normal child, but display negative attitudes towards the birth of a child with disabilities (Raina et al, 2005). Similarity, as confirmed by (Rudolph, Rosanowski, Eysholdt and Kummer, 2003), the burden of care giving role plays an important role in the course of anxiety. In the same way, as represented by (Buming, Gunal and Tukel, 2008), mothers' depression is also resulted from the greater demands of care giving burdened, earning a living and other responsibilities.

Additionally, the consequence of worrying for their children's future autonomous life; almost all respondent mothers were turned into depression and being stressed because they concerned that, due to the complexity of caring such children when they turned to old age or die; no one cannot take responsibility for take care of their children with CP. On the other hand, they also develop feeling of hopelessness for the incurability nature of this disability. Beside to this, they also bothered for the education of their children because of inaccessibility of educational facilities for such children in the school, lack of awareness among school leaders and difficult to found school's who accept their children without hesitation also add psychological distress.

The finding of the present study represents that, almost all respondent mothers of children with CP had limited social relationship with the members of their community including their relatives. Therefore, this reality increased the mother's emotional disturbance. In line with this, the less participation of mothers of children with CP with their social environment has been observed in previous research. Mothers of children with CP have little involvement in social get-together programs such as wedding ceremony and other social programs (Nimbalkar, Raithatha , and Shah, 2014). In Ethiopian context, it becomes very difficult for mothers of such children, because of misunderstanding of the causes for CP among the societies, cultural and traditional belief, insufficient support services for mothers and their children with CP, unpleasant social

interactions, and social isolation of the child; make the mothers to face frustration and experienced psychological distress.

5.2. Care giving Challenges Experienced by mothers of Children with CP

The finding of the present study illustrated that, caring of such children with CP are bored and demanding because, those children needs immediate help and lifelong caring. According to the finding of the present study, as the consequence of look after their children with CP in everyday life, such mothers of children with CP were experienced psychological distress, social isolation, physical health problem, financial and marital problems. The findings of the present study is similar to the previous research finding conducted by (Blacher & Bromley 1990; Raina et al., 2005) confirmed that, caring for a child with disability impacts on many aspects of a parent's life; which includes the problem in physical health, social, emotional, marital relationships, employment and financial status. Likewise, the study carried out by (Davis et al., 2009) described that, caring children with CP affects the life of parents, which includes, physical wellbeing, difficulty in maintaining social relationships, limit personal freedom, difficulty on marital relationships, financial stability and lack of social support from the community.

The burden of long term caring of children with CP also limits the mothers' social involvement. In addition to performing home based daily living activities; the matter of regularly assisting their children with CP disturbs mothers' emotional wellbeing. It was comparable with the prior studies; mothers' psychological distress was resulted from long term care giving duties and greater amount of energy consumed by these tasks (Murphy, Christian, Caplin, & Young, 2006; Myers, Mackintosh, & Goin-Kochel, 2009); Yantzi, Rosenberg & McKeever 2006). In the present study, all of the study participants experienced sleep disturbances and these add the burden of caring of their children with CP.

In this section the following sub-heading will be presented orderly; restricted social participation, physical health problem, marital problem and financial problem.

5.2.1. Restricted Social participation

The result of the present study demonstrated that, due to the care giving demands mothers' societal interactions were restricted. This social restriction is resulted from the negative

perception of the society and lack of knowledge, cultural belief and unable to find accurate information for the causes and the concepts of cerebral palsy which made by friends, relatives and the community. Besides to this, such mothers of children with CP do not like to involve in any social ceremonies because of their fearfulness and suppose that, may someone make some sarcasm by their child with CP. Consequently, some of the respondent mothers assume that, their children may not found a welcoming face from the societies then decide to limit their interactions with friends and various social groups. From the community members, some of them expected that, the reason why mothers of children with CP acquire such children is because of their previous bad activities done by them and now, they are punished by their sin or curses. In line with this, the present finding is supported by various previous studies, for instance, (Urimbenshi and Rhoda 2011; Wegner and Rhoda 2015; Lynch 2007) confirmed that, Communities in Africa often have a negative perception for people with disabilities because they believe that it is a punishment from the God.

In addition to this, the current study also revealed that, even their interactions with their husbands were limited, because due to continuous care giving role and different overloaded household activities at home make them busy and reduced their interaction. In parallel with this, the finding of the present study was supported by previous studies; their husbands left out and normally turn to extra marital affairs, neglect their wives and offer little or no support leading to marital breakdowns (UNDP, 2007). The reason why the mothers' interactions with their husband were became restricted, because of the time consuming nature of caring such children and insufficient time to interact with their spouses.

5.2.2. Physical Health problem

The findings of the present study showed that, most mothers of children with CP had physical health problem. Mainly these physical health problems are resulted from lifting and carrying of their children for an extensive period of time and moving a long distance. Those mothers had not have rest even in the transportation service either when they are moving to rehabilitation centers or doing household activities through carrying their children in a wide ranges of time in traditional way of carrying at back. Similarly, earlier study also confirmed by (Davis et al. 2009), he highlights that, lifting and carrying children on regular basis on their back might result

for overloaded physical pain. Due to long tern carrying and lifting of their children with CP; they encountered a shoulder and back pain problems. The researcher realized that, due to shortage and inaccessibility of physiotherapy services almost all respondent mothers of children with CP came from a long distance to rehabilitation center (CSE). In parallel with the finding of the present study the previous study also confirmed that, In many cases, it is mandatory for mothers to carry their children to their physiotherapy appointments because one of the most problem that restrict access of physiotherapy services is geographic location (Saloojee et al., 2006; Larivière, Bastien & Racine, 2011). This was supported by previous research finding; the traditional way of carrying children at the back utilized by the caregivers might give rise to increasing back pain (Dambi et al., 2015). Additionally, beside to this, the shortage of assistive devices in Ethiopia added the care giving burden to mothers of children with CP.

All respondent mothers also explained that, they have not sufficient time for themselves in their everyday life. As the result, they encountered relatively heightened degree of stress and depression. So, this leads to negative physiological health impacts. Likewise, the finding of the current study is supported by a number of previous research findings (e.g. Dambi and Jelsma 2014; Raina et al., 2005) described that, as long as, the high level of care required by a mothers for their child with CP with long-term functional limitations can become burdensome, and may affect both the physical and psychological wellbeing. In the same way, physical health challenges that emanated from excessive stress are resulted from constantly assisting their children in addition to the activities of daily living (Tonga and Duger 2008; Wijesingh, Fonseka, Hewage, (2013). In addition to these, it also confirmed by (Kaya et al., 2010; Davis et al., 2010), take care of these children, especially those who require unusual, extraordinary care and long-term support results in physical and mental stress for their mothers.

The finding of the present study revealed that, all of the respondent mothers considered that caring children with CP is bored at the higher age of the child's life. Additionally, these difficulties become seriously hard when the child's disability is severe or profound level and comprised of further disability. In contrast with the finding of the present study, the previous research finding suggest that, the fundamental issues related to caring for a child with CP remain similar throughout childhood and adolescence, although some indicated that the level of impact on these issues may be more pronounced in earlier years (Davis et al., 2009).

5.2.3. Marital problem

The tasks of care giving role for a child with CP often diminished the opportunity between couple to have a lovely family. The finding of the present study demonstrated that, caring children with CP have greater pressures on marital relationships and for one respondent mother it was a major reason to be separated. Correspondingly, a study carried out by (Rodrigues & Patterson, 2007), concluded that, couples (wife and husband) due to raising their children with disabilities who are at great risk of severe impairment could be a basis for the formation of divorce and eliminates love among them. As the result showed that, there is no repetition in divorce among couples. In contrast with the present study, a previous research carried out by (Wade et al., 2006), the result demonstrated that, families of children with disabilities are at least twice likely to divorce by the time the child is reached eight years old. So the care giving demands are the cause of divorce for families of children with CP. As the result of the present study demonstrated that, after the birth of their child with CP, for most mothers, their husbands cannot show lovely face and decrease their feeing of affection among them. In parallel with this, the previous study also confirmed that, in fact many people want to form married for several reasons including to acquire a child; however problems might be arise in marriage when the couple acquire a child with disabilities (Risdalle & Singer, 2004). In addition to this their relationships are obviously changed and cannot have sufficient time to interact each other. Due to the overloads of care giving responsibilities for such children with Cp; they had a little interaction with their husband's. So, these burdens create a marital problem in their life and they haven't lovely family. In line with this, previous research finding evidently revealed that, as a result of caring children with CP, the quality life of these mothers of children with CP is negatively affected (Olawale, Deih & Yaadar, 2013).

5.2.4. Financial burden

From the finding of the present study, the researcher found that, the main challenges of caring children with CP are financial burden. Financial burden is one of the most familiar challenges which experienced by mothers that linked to caring for a child with CP. As reported by the study participants, in order to provide adequate care and to meet the children's needs on a daily basis; wealth plays a vital role. The items such as, clothes, nappies/diaper/ and transportation service are mainly expensive and hard to provide for their children with CP. The finding of the present

study is parallel to the findings which was achieved by (Davis et al. 2009), the most necessary items required for caring a severely disabled child can be the most difficult to find and provide easily. Due to the nurturing role of their children with CP; some of respondent mothers lost a number of work opportunities and leave their jobs. Therefore, for most mothers, the major cause of socio-economic challenges are resulted from lack of employment opportunities and being unemployed also make mother to be depressed (Borst 2010).

Accordingly, this financial problem was often occurred in the reality by means of care giving burden, most mothers were unable to do and get work. As confirmed by earlier studies, financial burden occurs because of mainly parents leave their jobs and unable to do works due to the amount of time they spend to caring their child (Murphy et al., 2006; Thrush & Hyder, 2014). Similarly, financial problem mostly emerged when mothers were unable to found jobs due to the amount of time that they were expend a longer time in caring their children every day (Bourke-Taylor et al., 2010). Due to the result of this, they trouble to up bring their children effectively, unable to fulfill the unique needs of their children and never live a good quality of life as other mothers of non CP children. In line with the present study, this was supported by several previous studies, in most cases mothers were noted that just providing the basic necessities for children with CP is substantially costly (Davis et al., 2009; Thrush & Hyder, 2014).

Beside to this, some of the respondent mothers are afraid to apply and work in some private organization because of ashamed and confused may the organization unable to accept and allow them. These put forwarded them to be unable to find their hopes, dreams and self-confidence.

As explained by the study participants, most of them come from a far distance to take rehabilitation service and this adds the financial burden. Therefore, lack of accessibilities of rehabilitation services in Ethiopia is one of a basic problem and causes for financial burden for such mothers. Due to lack of income and financial pressure, some study participants forced to search access to funding financial aid, but because of bureaucracy they cannot obtain access to funding and financial as well as material assistance. In parallel, this was found in previous study that, access to funding is also a common barrier to care giving, as individuals struggle to access financial aid in order to cover the expenses that accompany their child's disability (Davis et al., 2009). Actually the process of submitting an application for financial aid is often time consuming and exhausting for caregivers (Davis et al., 2009; McManus et al., 2006). In addition

to this, some of the respondent mothers also described that, due to lack of knowledge, some organization was understood that, their child was not eligible for a grant and not qualified to get financial assistance. In the same way, the present study finding was matched with the previous research finding, lack of awareness that made by different organization to raise fund for financial donation for mothers of children with CP are argued that they do not qualify for financial aid because of unmeet for range of poverty to receive financial assistance (Resch et al., 2010).

5.2. Mothers interpersonal relationship with their children with cerebral palsy

The researcher realized from the finding of the study, almost all respondent mothers have a healthy and strong positive relationships with their children with CP. Moreover, they have been enthusiastic and fun when they engage themselves in recreational activities with their children. In contrast with the finding of the present study, Children with physical disabilities, including cerebral palsy, are at increased risk of disrupted relationships with their parents (Heffron, 2000). As unanimously approved by all study participants in order to have healthy relationship among mother and her child's with CP, the mother's positive attitude towards their children with disability is crucial. In parallel with this, this was supported by previous study (Pueschel, Bernier, & Weidenman, 1988) confirmed that, to have a better interaction among mother and children with CP, the mothers should have a positive attitudes to accept their children with his/her disability. Likewise, as confirmed by (Barfoot, Meredith, Ziviani, Whittingham, 2017), optimistic, encouraging and healthy parent–child relationships contribute for best possible child development but less is currently known about associations between the parent–child relationship and development for children with cerebral palsy.

As described by the study participants, they realized and accepted that, caring their children with CP are their major responsibilities through keeping their children's physical and psychological well-being. However, as responded by all respondent mothers, at the time of mother-child interaction, due to the existences of speech disorder on their children, there is a communication barrier. In most cases, a few respondent mothers were trouble to understand their children's feeling easily. Correspondingly, this was clearly distinguished in one earlier study; Mothers of children with a disability have reported difficulty understanding some of their child's cues (Bailey & Simeonsson, 1988). Additionally, this was also confirmed in other study; Mothers who are unable to obtain some guiding cues or feedback from their child may experience further

stress and which limits their interaction (Fewell, 1986). Because of their strain, many mothers of children with CP need a good sense of facial expression from their child but some children with CP cannot express their emotion in good health, either they are happy or not, but these was due to their speech disorder.

As reported by study participants, through time their children's speech problems were changed and they show greater progress in their communication abilities. Primarily such children use their usual form of communication, for instance, facial expression, gesture, eye-pointing, body movement (nodding of head), crying, murmuring etc. In the same way, this was done in earlier study, as confirmed by (Harris, 1982), Children mostly utilize their natural modes of communication, such as vocalization, gesture and body movements, and rarely use their augmentative system, unless requested to do. CP can have an effect on a child's ability to produce clear signals that are consistent over time. This lack of contingency may start from the very beginnings of interaction, with problems affecting the establishment of mutual gaze, as well as the later production of gestural, vocal, and verbal signals for intentional communication. In parallel with this, the previous study was also concluded that, it is likely that parents should adapt their communication to realize some feelings of effectiveness concerning their interaction with their children (Dunst, 1985).

Due to the responses of respondent mothers, as result of their children's stiffness as well as physical motor problem; regularly their children are dependent with them and cannot participate in the social activities.

5.3. Possible coping mechanisms employed by mothers of children with CP

Regarding the proposed theme, one of the main focus area in the present study is coping mechanisms that employed by mothers of children with CP. Essentially, those coping mechanisms are an approach which applied by such respondent mothers to adapt, manage and deal with stressful condition in regards to caring their children with CP. Mothers were utilized different coping mechanisms to handle and deal with stress.

The finding of the present study indicates that, the most common strategies that were employed by respondent mothers to cope with stress are; accepting the child's disability, being of patience/regulating once emotion/, religious coping/faith healing/ or through spiritual practices,

receiving social support, encouragement and advice from friends, families and community members are frequently taken by such respondent mothers. As explained by the study participants, from the above mentioned strategies; being of patience is most probably important mechanisms to manage the demanding situation. Compared from the others coping mechanisms, regulating once emotion or being of patience which means tolerating their children's disability extremely assisted them to accept their children's disability and offer internal freedom as well as strength to recover from stress. However, which does not mean that the remaining strategies are not significant. In this section we will discussed in detail how the respondent mothers employed those coping mechanisms.

5.3.1. Religious coping /faith-healing/ or spiritual practices

As indicated by all respondent mothers, they were beneficiary through applying this approach and commonly agreed for the positive consequence of practicing personal faith which was assisted them to cope from stress. Due to optimistic thoughts of such respondent mothers, they were committed and enthusiastic in utilizing such strategies to control and regulate their emotion. In regards to this approach a number of studies have been frequently done every time and confirmed that, being consistent in practicing religious way of life provide greater positive effect such as life satisfaction, happiness, improving self-confidence and other indicators of well being (Koenig, McCullough, & Larson, 2001). In the other study it was also correspondingly confirmed that, parents who are motivated by fundamental religious beliefs are more likely to displayed superior levels of cheerfulness (Biesinger & Arikawa, 2007).

In addition to this, when they involved longer time in praying of God, they got enormous forces to adapt the challenges in regards of caring their children with CP. Due to this, moreover the time, they go to place of worship (church/mosques) for praying. By applying such strategies they got future hope and develop self confidence. In parallel with this, several researches are carried out how parents are more likely to turn towards religion (Kamaruddin & Mamat, 2015), confirmed that, most probably parents of children with disability are to turn towards faith healing interesting in praying for reassurance and increased religious activities to feel less stress. In addition to this, religion coping strategies are the most common strategies used by parents coping with having a child with a developmental disability (Gray, 2006). Therefore, employing helpful coping methods, such as religion, forwarded to positive adaptations with positive outcome and

improved the general wellbeing one's life and the needs of the family (Norizan & Shamsuddin, 2010).

On the other hand, some respondent mothers were also believed that, they had been holy in acquiring such children because God selected them for the task of being mothers of such children and they had been given with the intention of this task with a better hidden positive reason they believed that, they are the chosen one. The God had chosen them for the reason to check them how they are consistently pray him and then to provide a heaven. In the other word, they expected that, their children's disability was not a fault of God but instead of making mistake; it was to select them to make his beloved one. In line with this, previous studies also confirmed, for instance a study explored by (Goren, 2015), also deals with how parents of children with disability spiritually made sense of their situation and confirmed that, parents were found to consider their children with disability as an designation of works that given from God to be kept their children in safe and secure way of life, they felt as they are blessed mothers, believed that their children with disability would provide them with a ticket to heaven, they thought that they were living with the correct angel of the God, felt proud to be parents of a heavenly child; and felt their children brought blessings to the house, luck to their lives, and peace to the family.

5.3.2. Receiving Social support

As the researcher discussed with study participants, receiving social support assisted them to cope from stress and the results obviously demonstrated that, all of them were unanimously agreed and got a number of benefits in applying such strategy. Correspondingly, several researchers were agreed that, employing social support as a means for resilience from stress can enhance individual's social and psychological well being. In parallel with the present study, this was supported by in various others earlier studies, such as, as noted by (Southwick, Vythilingam, and Charney, 2005), extremely positive social support can improve the individual's capability to cope and resilience from stress, help to keep against developing depression, decrease the functional consequences of psychological disturbance. Similarly, in the other study, with the evidence of (Grav, Hellzèn, Romild, and Stordal, 2012) those individuals who have well-built social and psychological support are less likely to be die than those who lose such sufficiency strong relationships.

As explained by the study participants, before acquiring social support and encouragement from their surrounding communities; they have inappropriate behavior like loneliness, committed to suicide oneself, restricted social participation and increased the risk of depression. But after forming a positive social network and obtaining support from their friends as well as from community member; they show a healthy behavioral changes and develop self regulation. In line with the present study, it has been approved in previous study that, having a prosperous and healthy social interaction can decrease the rate at which individuals involve in risky behaviors, avoid negative appraisal or decision for life, and increase being of faithfulness and treatment adherence (Rozanski, Blumenthal, and Kaplan, 1999; Fontana, Kerns, Rosenberg, and Colonese, 1989). The respondents described that, after gating recognition, respect and valued by others; it is most probably helped them to prevent and control stress and eager to practicing a good sense of worth for oneself. On the other hand, having a strong and well-built relationship in the society with a proper social support have a number of benefits, which includes: improving the ability to handle the demanding situations, eliminate and alleviate the effects of emotional distress, keeping lifelong and healthy emotional as well as psychological wellbeing, developing personal self-esteem, eliminating feeling of nothing to live in this world or suicide oneself, upholding and having good way of life as well as appropriate behaviors and committed to treat oneself.

5.3.3. Emotion regulation /Patience/

As responded by the study participants, regulating once emotion are essential to recover from stress and to achieve their responsibilities easily (i.e. to take care of their responsibilities towards caring their children with CP effectively). As the description of the respondent mothers, when they comprised and develop a positive insight for the condition of their child with CP, in parallel they had to acquire a good aspiration for their future life and free from stress. For details, the researcher also solicited them, the reason why they choose to be patience and their responses are because they believed that one day their child will recover from his/her disabilities and the God gave these tasks with a secret reason.

In parallel with the present study, previous study also confirmed that, the activation of positive emotions while coping with challenges can foster resilience (Tugade and Fredrickson, 2007). Having a positive emotion can allow people for a flexible attention, which can in turn improve

one's wellbeing. Therefore, through time and with repeated experiences of positive emotions, this broadened mindset might become habitual (Tugade and Fredrickson, 2007)

As clearly described by study participants, their ability to care their children efficiently are depend on their potential to control their sense of emotion and have positive feelings/ thoughts towards their children with cerebral palsy. Accordingly, the finding of the present study was similarly demonstrated in previous study; the extent to which the parent's capacity to be emotionally available and ability to consistently implement parenting practices based on fair and reasonable values and expectations is directly influenced by parent's emotion regulatory capacities (Harnett and Dawe, 2012).

5.3.4. Accepting the child's disability

All of the respondent mothers responded that, accepting their children's disability supported them to regulate and control their sense of emotion as well as got emotional wellbeing from shocking and challenging situation. As clarified by each study participants unanimously at the beginning, they had been challenged and it was difficult to accept their children's disability but after a time; they were decided to accept their children's diagnosis result (having cerebral palsy). In parallel, this was done in earlier study; according to (Sharief, 2014), in the early years of their children's age, parents are become challenged and find it quite stressful to accept the disability which exist in their children. After accepted their children's disability, they were become motivated to take care of their children without doubt and free from suffering in stress. In the same way, this was proofed in previous study, developing awareness for the truth concepts of disability by parents is a key element that could help families of children with disabilities to cop and adapt in care giving of their children with disabilities (Ross and Deverell, 2004).

Correspondingly, in our country Ethiopia, one study was also conducted by a famous professor in Ethiopia (Tirusew Tefera, 2005), the results are clearly stated for the significance of accepting the child's disability as follows, accepting and tolerating personal limitations by oneself, being strength in religious or praying the are major elements for unfolding and strengthening resilience. Likewise, one former study was also conducted by (Greeff and Nolting, 2013) confirmed that, next to the birth of a child with a disability, parents should adapt and adjust the situation to accept their children's disability.

The study participants are unanimously agreed for the momentousness of accepting the child's disability and developing positive outlook for their children with disability which brings power for mothers to adapt the stressful and demanding situation. Likewise, a study explored by (Bayat, 2007) the finding demonstrated that, developing and increasing positive perception for a stressful condition could be a shock absorber for the stress associated towards the responsibility of caring for a child with disability.

5.4. Limitation of the study

One of the major limitations of qualitative research is less being of generalize for large population, so, the present study also unable to generalize. In addition to this, the present study was conducted only in a qualitative approach with small number of participants. In order to found more capable of being generalized results, the future study should maximize the sample size and conduct in a mixed research through including different participants from different region in Ethiopia. Furthermore, the researcher also recommended for the future researchers, in order to realize the significance differences of psychosocial challenges among mother, it would be better the sample comprised of biological mother who have maid and who haven't personnel at home otherwise, among legal care giver and biological mother, or psychosocial difference among mothers and fathers.

CHAPTER SIX

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 Summary

The purpose of the present study is to explore the psychosocial challenges encountered by mothers of children with cerebral palsy in Addis Ababa at Cheshire service Ethiopia.

Accordingly, in order to achieve the above purpose, the researcher proposed the following leading research questions:

1. What are the psychological challenges faced by mothers of children with CP?
2. What are the Care giving Challenges that experienced by mothers of Children with CP?
3. What look like the mothers' interpersonal relationship with their children with CP?
4. What are the possible coping mechanisms that are employed by mothers of children with CP?

The present research issue is qualitative in nature and qualitative research approach with phenomenological research design was employed. In order to find out relevant answer for the above basic research questions; the researcher preferred thirteen (13) mothers of children with CP particularly in the present time their children attend developmental physiotherapy service at Cheshire service Ethiopia. All of the key informant are biological mother of children with CP and meet the inclusion or eligibility criteria of selection. Such respondents are selected by using purposive sampling methods. The data was collected through an in-depth semi-structured interview and focus group discussion. From the total of thirteen respondents, seven of them were participated in individual face to face interview and the remaining six were involved in focus group discussion. The data were analyzed qualitatively using the thematic analysis approach.

From the result of the data analysis, the following major findings were obtained and arranged.

Summary of the major findings were presented below:

1. In the present study the major emerged themes demonstrate that, before the birth of their children with CP, all of the study participants had not had any concept regarding to cerebral palsy. Even after the birth of their child with CP, most of the participants were expected as a

health problem and did not understand the permanent nature of disability. The majority of children with CP were screened as having CP between births to 9th month.

2. After realizing the realities of unexpected results of their children's diagnostic result and comprehending the fact concepts of CP, such respondent mothers were faced greater psychological disturbances which comprised of, shocking, disheartened, anxious, frustration, stressed, and depression. Due to suffering in a greater psychological distress, some of the respondent mothers were decided to suicide themselves; this was done because of ashamed by their children's disability and knowing the complexity and lifelong care and treatments of their children with CP.
3. Due to recognizing the heartbreaking news of the life of their children's condition, a number of sign of depression and stress were evidently observed on mothers of children with CP. mainly the potential sign of depression and stress which was obviously experienced by respondent mothers are; crying, unhappiness, feeling of frustration ,loss of desire of food, blaming oneself or self guilt, sleeplessness, feelings of sorrow, unresponsiveness, leaving oneself from the social group (feeling of isolation or loneliness), wanted to live in an isolated room for a long period of time, sign of discouraging and disappointed for their child's future life and showing feeling of inferiority
4. The result of the present study demonstrated that, the major source of depression and stress that experienced by the respondents are; seeing their children's typical age peer groups, feeling for their children's education, considering for the future life of their children's independent life, feeling for the burden of lifelong car giving demands, inaccessibility of physiotherapy service, financial problem, stigmatization made by others, losing their previous work, other work opportunities and being unemployed, feeling of the incurability nature of their children's disability, and lack of awareness among school leaders to accept their children with CP.
5. According to the result of the study, mothers of children with CP faced discrimination even by their family members (mainly by spouses) to the whole community members. This was due to misconception for the causes of CP which lowers the mothers' dignity and to feel inferiority for a mother of such children.
6. The result of the present study indicated that, being of shocking, depression, constant worry and feeling of suicidal are the usual initial reaction for the mothers of children with CP and

mainly overwhelmed, when they heard for the unexpected diagnostic results of their children with the consequences of sorrow, grief, for the reality of missing hopes and dreams.

7. The result of the present study demonstrated that, caring of such children with CP is extremely bored, demanding, painful, and devastated for mothers. Therefore, these car giving demands are consequences the following problem on the mother's life; psychological distress, social isolation, financial and marital problems physical health problem, limit personal freedom, lost of work opportunities and become unemployed, and add burden on home based daily living activities.
8. The majority of the respondent mothers were experienced greater shoulder and back pain problem that resulted from carrying up and lifting of their children with CP for a longer time. They are carrying their children even in transportation as well as doing home based activities. The traditional way of carrying their children at the back is the main causes a back pain problem.
9. Due to their innate love, all of the respondent mothers have strong positive physical attachment and healthy interpersonal relationship with their children with CP.
10. The most common coping mechanisms that employed by the respondents are accepting their children's disability, being of patience or regulating once emotion, religious coping/faith healing/ or through spiritual practices, receiving social support from friends, community members and related professionals.
11. Even though, from the mentioned coping strategies, the most important mechanisms that can assist them to recover from stress are being of patience because after regulating once emotion, they were able to accept their children's disability, acquire psychological strength to take care of their responsibility towards caring their children with CP and to administer the challenging situation.
12. The last but not the least, the majority of the respondent mothers was challenged to accept their children's disability in the early period of their children's age. However, after accepting their children's disability, such mothers were believed as they had been holy in acquiring such children and selected for the task of being mothers of such children and they had been given with the intention of this task with a better hidden reason. Similarly, they

also supposed that, their children's disability was not a fault of God. Rather than making mistake it was to select them as his beloved one.

6.2. Conclusions

- Before the birth of their children with CP there is lack of accurate information in regards to the concept of CP. Even after realizing their children's diagnostic result, they expected as a health problem and CP could be cured medically and their children could be recovered immediately form their disability. But after knowing the truth, shocking is normal and one of the main initial reaction for mothers of children with CP.
- In regards to the burden of care giving demands, all of the respondent mothers were shocked and overwhelmed because, caring of such children is extremely painful and devastated for mother with the consequences of sorrow, grief, for the reality of missing hopes and dreams. These consequences, the mothers to be faced psychological distress, social isolation, financial and marital problem, physical health problem (particularly, shoulder and back pain problem), lose of work opportunities and become unemployed, and add burden on home based daily living activities.
- One of the cause of psychological challenges is discrimination and this was due to misunderstanding for the causes of CP that made by the community. In some regards, some of the community members considered that, the birth of such children with CP is due to wrong doing/sin or curse committed by the family members. As a result of this, mothers develop feeling of inferiority and ashamed by their children's disability.
- As the report of the study participants, due to intrinsic feeling of affection for their children with CP, the respondent mothers have a strong positive physical attachment and healthy interpersonal relationship with their children with CP. In addition to innate love, they also have immediate eye contact even they are on the work because of their fearfulness may their children acquire further impairment.
- In order to make the demanding conditions to be more manageable, mothers of children with CP employed several coping mechanisms. Therefore, the most common coping mechanisms that employed by respondent mothers are, accepting their children's disability, regulating once emotion /being of patience/, religious coping /faith healing/or through spiritual practices, receiving social support from friends, community members and other

professionals who are worked with children with CP. However, they were challenged to accept their children's disability in the early period of their children's age.

6.3. Recommendation

- The health care professionals, physiotherapist, counselor, and special needs educator should play their vital roles in explaining deeply about the concepts of cerebral palsy for the community member, empowering mothers how to manage demands towards the care giving responsibilities as well as how to overcome the stressful situation. Besides to providing physiotherapy service for such children, mothers should receive relevant skill based intervention that could accommodate them to caring their children effectively. Additionally, they could take part in raising awareness and should ensure for the social acceptance of such mothers of children with CP. the awareness raising training should started from the family members of children with CP.

- Families of children with CP should build friendly, best possible to develop a mutual helping system at home environment. They should be empathy and actively engaged in reducing mother's anxiety for the future life, education and independent living of their children with CP.

- The government should access developmental physiotherapy services in the country. Governmental institution including hospitals and school should employ and provide assessment facilities for such children with CP.

- The societies must build up a positive perception towards mothers of children with CP and encouraged them to participate in the social group equally as other community members.
- The school community should develop optimistic attitudes and welcoming school environment to accept such children with CP. As much as possible the physical, educational as well as the attitudinal barrier that existed in school could be adapted and modified to accept such children with CP and improve their engagement in the regular classroom.

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Appendix A

Consent form for parents

Addis Ababa University

College of Education and Behavioral studies

Department of Special Needs Education

My name is Oumer Seid Hassen. I am a graduate student in Addis Ababa University department of special needs education. The implementation of the present study is to fulfill the requirements for the degree of master art in special needs education. This interview guide is arranged to collect data from mothers having children with cerebral palsy.

The general objective of the present study is to explore psychosocial challenges encountered by mothers having children with cerebral palsy. The result of this study will contribute a lot; such as, the mothers of children with cerebral palsy will understand how to cope the problem related caring their children with disability, the professionals who are working with children with cerebral palsy will acquire additional knowledge and give more consideration when designing and implementing intervention, some mothers of children with cerebral palsy will gain lived experiences from other experienced mother how to cope the stressful situation and adapt the life challenges, In addition to this, the finding of the present study will provide hints for the study area (Cheshire service Ethiopia) and other organization to show the correct ways of providing intervention and giving more consideration for mothers of children with CP.

The information you provide are extremely important input in the direction and accomplishments of this study, so please try to be honest, and careful. I would like to express my deepest gratitude for your active participation. The participation is not obligatory rather it is voluntary and if you are not interested you will dropout either at beginning or during interview session. The information that you will provided will be kept confidentially and only applicable for the academic purposes of this study. You have to know that, this interview may take a minimum of one hour and during interview session you will be recorded.

Thank you again and I appreciate you for your willingness to participate in the interview.

Mother's sign _____date_____.

Part one:

Background Information

1. Maternal relationships

   Biological mother ☐

   Legal care giver ☐

   Others ☐

2. Marital status

   Married ☐

   Single ☐

   Divorce ☐

3. Mother's Age ___

4. Educational status _____

5. Mother's occupation _____

6. Child's age_____

7. The child's age during screened out _____

8. Child's sex_____

9. Child's grade level _____

10. Does your child's with CP have siblings? Yes ☐ No ☐

    If yes number of siblings Male ☐ Female ☐

Part two

Interview guides

1. What are the psychological challenges that faced by mothers of children with CP?

1.1. Did you know about the concept of cerebral palsy before your child's with CP born?

1.2. What did you feel/what is your initial reaction when your child screened as having cerebral palsy? Did you have any symptoms of anxiety/disturbance associated with the result of diagnosis? Can you tell me why you are disturbed?

1.3. What do you feel when you see your child's peers without cerebral palsy in your surrounding?

1.4 What do you feel when you think about your child's future?

1.5 Do you believe that, I am strong emotionally and mentally? If your answer is yes, how you are emotionally strong? If No, why?

1.6 Do you live with your husband? If ye, what is your husband's attitude towards you and your child? What look like the status of accepting the child's disability?

2. What look like the mother's interpersonal relationship with their children with CP?

2.1 Can you explain the nature of your interaction with your child with cerebral palsy?

2.2 Do you think that, ''I have a good personal relationship with my child with cerebral palsy''? If YES, what it look like? If not, why?

2.3 What look like your eye contact and how you give attention for your child? Like, understanding your child's needs, an immediate follow up etc

2.4 How can you communicate and understand your child?

2.5 How do you spend your leisure time with your child?

2.6 How can you play/enjoy with your child and what type of entertainment do you use to relax him/her? Like puzzles, fairy tales, telling jokes, funny story, go to playground or others

3. What are the car giving challenges that faced by mothers of children with cerebral palsy?

3.1. Do you believe that the care giving process for children with CP is difficult? If yes, how and why it is makes difficult? If No, why?

3.2 Is there any sign of psychological depression due to thinking the provision of life long term care and treatment of your children with CP? If yes, how you become psychologically depressed?

3.3 What are the impacts of care giving challenges in your daily life? Like marital status, occupation, social participation, in your health, difficulties in holidays etc

3.4 do you faced any socio-economic challenges or lack of employment opportunities because of caring your children with CP? If yes, explain it?

3.5 What do you feel when you think for the consistencies and the time-consuming nature of caring children with CP?

3.6 How the severity of the child's disability and age increase the care giving challenges?

3.7 How the conditions of caring children with CP affect the quality of your life?

4. What are the possible coping mechanisms that are used by mothers of children with cerebral palsy?

4.1 Is there a strategy that you used to reduce stressful events that you experience in your child's day to day life? If so, would you explain those methods?

4.2 how important are the strategies you have used to reduce stress, you have while raising your child? Which of the methods did you find most useful?

4.3 How do you believe in religious/spiritual practices to assist you in coping with the problem?

4.4 How m you involve yourself in religious or spiritual activities to reduce stress?

4.5 Do you believe that, accepting the child's condition is a coping mechanism to reduce stress? If yes how? How can you accept your child's disability as a fact of life?

4.6 How do you believe that receiving support, encouragement and advice from friends, family, and community is important coping mechanisms?

Appendix B:

Focus Group Discussion (FGD) guide for mothers of children with cerebral palsy.

1. What do you feel to look like as a mother of children with cerebral palsy?

2. What do you feel, when you know the complexity of caring children with CP?

3. What coping mechanism you were employed to adapt the stressful condition and which techniques are the most helpful for your life?

4. How the conditions of your child's life influence your psychological wellbeing?

5. How can mother worried for the future life of her children with CP?

6. What look like your daily interaction with your children with CP? How differ from non cerebral palsy children?

7. Do you have any suggestion; what should be done to support caregivers of children with CP and how mothers of children with CP should adapt the problem?

Thank you again for participation

Appendix C
የወላጆች የውል ስምምነት ቅጽ

አዲስ አበባ ዩኒቨርሲቲ

የትምህርት እና ባህሪ ጥናት ኮሌጅ

የልዩ ፍላጎት ትምህርት ክፍል

ኡመር ሰይድ እባላልሁ፡፡ በአዲስ አበባ ዩኒቨርሲቲ በልዩ ፍላጎት ትምህርት ክፍል ውስጥ የድህረ-ምረቃ ተማሪ ነኝ፡፡ ይህ ጥናትና ምርምር የሚካሄደው በልዩ ፍላጎት ትምህርት ክፍል የድህረ-ምረቃ ትምህርቱን ለማጠናቀቅ መስፈርቱን ለማሟላት ነው፡፡

የዚህ ጥናት አጠቃላይ ዓላማ ሴሬብራል ፓልሲ ያለባቸው ልጆች እናቶቻችውን ያጋጠማቸውን የስነ-ልቦና እና የማህበረሰባዊ ችግሮች ለመዳሰስ ነው.፡፡ የዚህ ጥናት ውጤት በርካታ አስተዋጽኦዎች ሲኖሩት፤ ከነዚህም መካከል እናቶች ከልጆቻቸው የአካል ጉዳተኝነት ጋር የተያያዙ የስነ-ልቦና እና የማህበረሰባዊ ችግሮችን እንዴት ለመቋቋም እንደቻሉ እና ምን አይነት ዘዴዎችን እንደተጠቀሙ ለመረዳት፣ ሴሬብራል ፓልሲ ላለባቸው ልጆች እገዛ የሚያደርጉ ባለሙያዎች ተጨማሪ እውቀት እንድያገኙ እና ለእናቶች የበለጠ ትኩረት እንድኖራቸው ማለትም ለልጆቹ እገዛ የሚደረጉ ተግባራትን ሲያቅዱ ለናቶችም ማቀድ እንዳባቸው ለማሰገንዘብ፣ በቅርብ ጊዜ ልጆቻቸው ላይ ጉዳት የደረሰባቸው እናቶች እንዴት የውጥረት ሁኔታን መቋቋም እንደሚችሉ እና የሕይወት ፈተናዎችን ማለፍ እንደሚችሉ ከሌሎች እናቶች ልምድ እና የሕይወት ተሞክሮዎችን እንድካፈሉ ያደርጋል፡፡

በዚህ ጥናት ውስጥ እርሶ የሚሰጡን መረጃ ለጥናቱ እጅግ በጣም ጠቃሚ ግብዓት ስለሆነ እርሶም ታማኝ እና ሐቀኛ በመሆን በጥንቃቄ መረጃዎችን ለመስጠት ይሞክሩ፡፡ ስለሆነም እርሶም ለሚያደርጉት ንቁ ተሳትፎ ያለኝን ጥልቅ ምስጋናዬን ለመግለጽ እወዳለሁ፡፡ በዚህ ቃለ መጠይቅ ውስጥ ተሳታፊነት በፈቃደኝነት ላይ የተመሰረተ ሲሆን ከቃለ መጠይቁ በፊትም ሆነ መሃከል ላይ ቃለ መጠይቁን ለማቋረጥ ከፈለጉ ሙለ በሙለ የሚችሉ መሆኑን አረጋግጥልዎታለሁ፡፡ በመሆኑም የእርሶ መረጃ ለዚህ ጥናት አላማ ብቻ የሚውል እና ሚስጥራዊነቱ ሙሉ በሙሉ የተጠበቀ ሲሆን እንድሁም የሰጡን መረጃ ይህ ጥናት ከተጠናቀቀ በኋላ ሙለ በሙለ እንደሚጠፋ አረጋግጥልዎታለሁ፡፡

ይህ ቃለ መጠይቅ ቢያንስ አንድ ሰዓት ሊፈጅ የሚችልና በቃለ መጠይቁ ወቅት አንዳንድ ግሊዊ ወይም ምኞት የማይሰጡ ጥያቄዎች ሊኖሩ እንደሚችሉ በቅድሚያ እያሳወኩ በቃለ መጠይቁ ላይ ለመሳተፍ ፈቃደኛ ስለሆኑ በድጋሚ አመሰግናለሁ፡፡

የወላጅ ፊርማ ----------ቀን ----------

ክፍል አንድ

የቃለ-መጠይቅ ተሳታፊ ግለ ሁኔታ/ማንነት/መረጃ

1. **የእናትና ልጅ ዘመድና**

   ወላጅ እናት ☐

   ህጋዊ ሞግዚት ☐

   ሌላ ካለ ☐

2. **የጋብቻ ሁኔታ**

   ያገባ ☐

   ያላገባ ☐

   የተፋታ ☐

3. **የእናት ዕድሜ** ___

4. **የትምህርት ደረጃ** _____

5. **የእናት የሥራ አይነት** _____

6. **የልጅ ጾታ**_____

7. **የልጁ ዕድሜ** _____

8. **ልጁ ሴሬብራል ፓልሲ እንዳለበት በምርመራ የታወቀበት እድሜ** _____

9. **የልጁ የክፍል ደረጃ** _____

10. **ልጁ/ጅቷ ወንድምና እህት አለው/ላት? አለው/ላት** ☐ **የለውም/ትም** ☐

    ካለው የልጁ/ጅቷ ወንድምና እህት ብዛት

    ወንድ ☐ **ሴት** ☐

ክፍል ሁለት

የቃለ መጠይቅ መመሪያዎች/Interview guides/

1. What are the psychological challenges faced by mothers of children with CP?

1.1 ይህን ልጅ ከመውለድዎ በፊት ስለ ሴሬብራል ፓልሲ ምንነት ያውቁ ነበር?

1.2 ለመጀመሪያ ጊዜ ልጅዎ ሴሬብራል ፓልሲ እንዳለበት ሲረጋገጥ ምን ተሰማዎት? ከምርመራ ውጤቱ ጋር ተያይዞ የመረበሽ ምልክት ተሰምቶታልን?ከምን አንጻር እንደተረበሹ ሊያብራሩልኝ ይችላሉን

1.3 ሴሬብራል ፓልሲ የለባቸውን የልጅዎን የእድሜ አቻዎች ሲያዩ ምን ይሰማዎታል?

1.4 የልጅዎን የወደፊት የሕይወት ሁኔታ ሲያስቡት እርስዎ ምን አይነት ስሜት ይሰማዎታል? ለምን

1.5 እኔ በስሜትም ሆነ አእምሯዊ ጠንካራ ነኝ ብለው ያምናሉን? የእርስዎ መልስ አዎ ከሆነ, እንዴት ጠንካራ አንደሆኑ ቢያብራሩልኝ? መልስዎ ጠንካራ አይደለሁም ከሆነ, ለምን?

1.6 ከባልተቤትዎ ጋር ነው አብረው የሚኖሩት? መልስዎ አዎ ከሆነ ባልተቤትዎ ለእርሶ እና ለልጅዎ ያለው አመለካከት ምን ይመስላል? የልጅዎን የአካል ጉዳተኝነት የመቀበል ወይም ያለመቀበል ሁኔታ ምን ይመስላል?

2. What is the mother's interpersonal relationship with their children with cerebral palsy?

2.1 ሴሬብራል ፓልሲ ካለበት ልጅዎ ጋር ያለዎት ግንኙነት ምን ይመስላል? ጥሩ የሆነ ግላዊ ግንኙነት አለኝ ብለው ያስባሉን? መልስዎ አዎ ከሆነ በምሳሌ አስደግፈው ቢያብራሩልኝ? አይደለም ከሆነ ፣ ለምን?

2.2 ከልጅዎ ጋር ያለዎት የዓይን ቁርኝት እና ትኩረት ሰቶ የመከታተል ሁኔታ ምን ይመስላል? ለምሳሌ የልጅዎን ፍላጎት የመረዳት፣ ጉዳት እንዳይደርስበት የመከታተል ወዘተ

2.4 እንዴት ከልጅዎ ጋር ሃሳብ መለዋወጥ ፣ መግባባ እና መረዳዳት ይችላሉ?

2.5 የእረፍት ጊዜዎን ከልጅዎ ጋር እንዴት ያሳልፋሉ? እንዴትስ ይጫወታ/ ይዝናናሉ? እንድሁም ልጅዎን ለማዝናናት ምን ዓይነት መዝናኛዎችን ይጠቀማሉ? ለምሳሌ እንደ እንቆቅልሾች ፣ ተረት ተረቶች ፣ ቀልድ መናገር ፣ አስቂኝ ታሪክ ፣ ወደ መጫወቻ ስፍራ በመውሰድ ወይም ሌሎች

3. What are the car giving challenges faced by mothers of children with cerebral palsy?

3.1ሴሬብራል ፓልሲ ላለባቸው ልጆች እንክብካቤ የማድረጉ ሂደት አስቸጋሪ ነው ብለው ያመናሉን? መልስዎ አዎ ከሆነ፤ እንዴት እና ለምን አስቸጋሪ ነው አሉ? አስቸጋሪ አይደለም ካሉ፤ ለምን?

3.2 ሴሬብራል ፓልሲ ላለበት ልጅዎ በሚያደርጉት እንክብካቤን ሳቢያ በዕለት ተዕለት ሕይወትዎ ላይ ምን አይነት ተጽእኖ አሳድሮቦት ያውቃል? ለምሳሌ በጋብቻ፣ በሥራ፣ በማህበራዊ ተሳትፎ፣ በበዓላት ወቅት ወዘተ

3.3 ለልጅዎ በሚያደርጉት እንክብካቤ ምክንያት በኢኮኖሚያዊና ማህበራዊ ትስስረዎ ላይ ወይም የስራ ዕድል የማጣት ችግር አጋጥሞት ያውቃልን? መልስዎ አዎ ከሆነ፤ቢያብራሩልኝ?

3.4 ሴሬብራል ፓልሲ ላለበት ልጅዎ የረጅም ጊዜ እንክብካቤ የሚያስፈልገው እና እንክብካቤው ብዙ ጊዜ የሚፈጅ መሆኑን ሲያስቡ ምን የሰማዎታል?

3.5 የልጅዎ የአካል ጉዳተኝነት ከባድ ደረጃ ላይ መሆን እና የእድሜው ሁኔታ በሚያደርጉት እንክብካቤ ላይ እንዴት ችግሩን ሊያባብሰው ይችላል?

3.6 ሴሬብራል ፓልሲ ያለበትን ልጅዎን የመንከባከብ ሁኔታ እንዴት በሕይወት ጥራት ላይ ተጽዕኖ ሊያሳድር ይችላል?

3.9 ሴሬብራል ፓልሲ ላለበት ልጅዎ ለረጅም ጊዜ በሚያደርጉት እንክብካቤ ምክንያት የተነሳ ምን አይነት የስነ-ልቦና ተጽኖ አሳድሮቦት ያውቃል?

4. What are the possible coping mechanisms that are used by mothers of children with cerebral palsy?

4.1 ልጅዎን በሚያሳድጉበት ወቅት ለሚያጋጥምዎት የሕይወት ተግዳሮቶችን ለመቀነስ የተጠቀሙባቸው ዘዴዎች አሉን? ካሉ፤ እነዚህን ዘዴዎች ቢገልጹልኝ?

4.2 ልጅዎን ሲያሳድጉ ያጋጠመዎትን ውጥረት/ጭንቀት/ ለመቀነስ የተጠቀሙባቸው ስልቶች ምን ያህል ጠቃሚ ሁነው አግኝተዋቸዋል? የትኛውስ ዘዴ ይበልጥ ጠቃሚ ሆኖ አግኝተውታል?

4.3 በሀይማኖታዊ/መንፈሳዊ/ እምነቶች ላይ መዘውተር የሚገጥሞትን ችግር ለመቋቋም ምን ያህል ይረዳኛል ብለው ያምናሉ?

4.4 የልጁን የአካል ጉዳተኝነት ሁኔታ አምኖ መቀበል ጭንቀትን/ውጥረትን/ ለመቀነስ ከሚረዱ ዘዴዎች/መፍትሄዎች/ መካከል ነው ብለው ያምናሉን? መልስዎ አዎ ከሆነ እንዴት ሊረዳ ይችላል?

4.5 ጭንቀትን ለመቀነስ ሲሉ በሃይማኖታዊ ወይም በመንፈሳዊ እምነቶች ላይ አዘውትረው ይሳተፋሉን? መልስዎ አዎ ከሆነ ምነ ምን ያህል ጠቃሚ ሁኖ አገኙት/ምን ያህል ጠቅሞኛልብለው ያምናሉ?

4.7 ከጓደኞች፣ ከቤተሰብ እና ከማህበረሰቡ ድጋፍ እና ማበረታቻ እንድሁም ምክር ማግኘቱ፤ ችግሮችን ለመቋቋም የሚረዱ አስፈላጊ ዘዴዎች ናቸው ብለው ምን ያህል ያምናሉ?

Appendix: D

Focus Group Discussion (FGD) guides for mothers of children with cerebral palsy.

1. የሴሬብራል ፓልሲ ያለበት ልጅ እናት መሆንን እንዴት ያዩታል?

2. ሴሬብራል ፓልሲ ያለበትን ልጅ መንከባከብ አስቸጋሪነቱን ስታውቁ ምን ተሰማችሁ?

3. ሴሬብራል ፓልሲ ካለበት ልጃችሁ ጋር አብራችሁ ስትኖሩ ምቹ ሁኔታዎችን ለመፍጠርና አስቸጋሪ ሁኔታዎችን ለመቋቋም ስትሉ ምን አይነት ዘዴዎችን ተጠቅማችሁ ታውቃላችሁ? ከተጠቀማችሁት ዘዴዎችስ የትኞቹ ይበልጥ ጠቃሚ ሁነው አገኛችኋቸው?

4. ሴሬብራል ፓልሲ ያለበት ልጅ የሕይወቱ ሁኔታ በእናቱ ሥነ-ልቦናዊ ደህንነት ላይ እንዴት ተጽዕኖ ሊያሳድር ይችላል?

5. አንድ እናት ሴሬብራል ፓልሲ ስላለበት ልጇ የወደፊት ሕይወቱ ስታስብ ከምን አንጻር ሊያስጨንቃት ይችላል?

6. እናት ሴሬብራል ፓልሲ ካለበት ልጇ ጋር ያላትን የዕለት ተዕለት ግንኙነት/ቅርርብ/ ምን እንደሚመስል ብታብራሩልኝ? ይህ ግንኙነት ሴሬብራል ፓልሲ ከሌለባቸው ልጆቿ ጋር በምን እና እንዴት እንደሚለያይ ብትብራሩልኝ?

7. ሴሬብራል ፓልሲ ያለባቸውን ልጆች ተንከባካቢ እናቶችን ለማገዝ ምን መደረግ እንዳለበት እና እናቶች ችግሩን እንዴት መላመድ/መቀነስ/ እንደሚችሉ ተጨማሪ ሀሳብ ካለዎት ቢያካፍሉን?

ስለተሳተፋችሁ አመሰግናለሁ