



ADDIS ABABA UNIVERSITY
SCHOOL OF GRADUATE STUDIES
COLLEGE OF EDUCATION AND BEHAVIOURAL STUDIES
DEPARTMENT OF SPECIAL NEEDS EDUCATION

LIVED EXPERIENCES OF SINGLE MOTHERS OF CHILDREN WITH INTELLECTUAL
DISABILITY: CASES FROM CENTER FOR MENTALLY CHALLENGED CHILDREN

BY:

ROMAN NEGASH

ADVISOR

DR. DANIEL DESTA

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ADDIS ABABA

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ROMAN NEGASH

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ROMAN NEGASH

Approved by Board of Examiners

External Examiner

Signature

Date

Internal Examiner

Signature

Date

Advisor

Signature

Date

DECLARATION

I, Roman Negsah declare that this thesis is my own work and it has not been submitted for any other degree or examination at any other university or institution. It is submitted in the partial fulfilment of the requirements for the degree of masters of Art in special needs education by coursework and research report in the Department of Special Needs Education, in Addis Ababa University.

Name _____

Signature _____

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Table of Contents

Acknowledgements.....	i
List of Acronyms and Abbreviation.....	ii
Table of Contents.....	iii
Abstract.....	vii
CHAPTER ONE.....	1
INTRODUCTION.....	1
1.1. Background of the study.....	1
1.2. Problem Statement.....	4
2. Objectives of the Study.....	6
2.1. General Objective.....	6
2.2. Specific Objectives.....	6
2.3. Research Questions.....	6
2.4. Significance of the Study.....	7
2.5. Definition Of Key Concepts.....	7
2.6. Organization of the Thesis.....	7
CHAPTER TWO.....	8
REVIEW OF RELATED LITERATURE.....	8
2.1. Single Motherhood.....	8
2.2. Intellectual Disability.....	9
2.3. Major Challenges of Single Mothers Having Children With Intellectual Disability.....	9
2.3.1. Lack of Knowledge And Misunderstanding of Disability.....	10
2.3.2. Lack of Financial Support And Employment Opportunity.....	11
2.3.3. Lack of Access And Affordable Service For Diagnosis.....	12
2.3.4. lack of Partners' Support And Poor Social Relationship.....	13
2.4. Effects of Challenges.....	13

2.4.1.	Un Healthy Psychological And Emotional State	13
2.4.2.	Weak Physical Health Condition	14
2.5.	Coping Strategies	14
2.5.1.	Family and Community Support.....	14
2.5.2.	Hope, Faith And Developing Relationship.....	15
2.6.	Perceived Needs.....	15
2.6.1.	Policies, Laws And Practical Implementation	16
2.6.2.	Information on Support Systems	17
2.6.3.	Guidance and Counseling	17
2.6.4.	consideration of Family Needs In Support System.....	17
CHAPTER THREE		19
RESEARCH DESIGN AND METHODOLOGY		19
<u>3.1.</u>	Research Design.....	19
<u>3.2.</u>	Research Area	20
<u>3.2.1.</u>	Brief Description about the Center for Mentally Challenged Children (CMCC)...	20
<u>3.3</u>	Sampling Strategy	21
<u>3.4</u>	Sources of Data	22
<u>3.5</u>	Data Gathering Methods	22
<u>3.6</u>	Method of Data Analysis.....	24
<u>3.7</u>	Ethical Considerations.....	24
3.7.1	Informed Consent	25
3.7.2	Anonymity	25
3.7.3	Confidentiality	25
3.7.4	Privacy	25
3.7.5	Storage of Data and Access To Results.....	25
3.8	Self- Reflectivity and Avoiding Bias	26

CHAPTER FOUR.....	27
FINDINGS AND ANALYSIS OF RESULTS	27
4.1. Introduction	27
4.2. Brief Descriptions of Participants	27
4.3. Findings.....	30
Table 1 Themes and Sub-Themes With Short Description.....	30
<u>4.3.1. Journey to The Unexpected Reality</u>	31
a) Traditional Ways	32
b) Medical Diagnosis.....	32
c) Information from Individuals	33
4.3.2. Major Care Giving Challenges.....	33
a) Death or Separation Of Partner	34
b) Family/ Societal Reactions Towards Disability	35
c) Poor Diagnosis And Referral System.....	36
d) Lack of Financial Support and Job Opportunity	37
e) Lack of Schools or Training Centers for their Children.....	38
f) Uncertainty about the Future	40
4.3.3 The Effects of Challenges	41
a) Psychological Strains.....	41
b) Emotional Disturbance.....	42
c) Health Related Problems	42
d) Social Isolation.....	43
e) Financial Crisis.....	44
f) Spiritual Crisis	44
4.3.4 Copping Strategies	44
a) Spiritual Believes.....	45
b) Hope	46

c) Developing Relationships.....	46
4.3.5 Future Perspectives: Mothers' Point of View	47
CHAPTER FIVE	50
DISCUSSION.....	50
CHAPTER SIX.....	60
SUMMARY, CONCLUSION AND RECOMMENDATIONS.....	60
6.1. Summary	60
6.2. Conclusion.....	61
6.3. Recommendations	61
REFERENCES	63
APPENDIXS.....	71

Acronyms and Abbreviations

ADHD: Attention Deficit High per Activity Disorder

CSA: Central Statistics Authority

CMCC: Center for Mentally Challenged Children

CWDs: Children with Disabilities

CWID: Children with Intellectual Disability

DHS: Demographic and Health Survey

EECMY- DASSC-ECYCP: Ethiopian Evangelical Church Mekane Yesus- Development And

Social Service Commission- Education Child and Youth Care Program

FGD: Focus Group Discussion

ID: Intellectual Disability

KNH: Kindernothilfe

PWDs: People with Disabilities

QOL: Quality of Life

Abstract

Having a child with disability is challenging for many parents in many African countries. Mothers, in most cases, single once are those who face additional burdens as they are primary care givers and soul providers to their children with disability in addition to other regular responsibilities. This study was conducted aiming to explore the life of Single Mothers of Children with Intellectual Disability in the case of Center for Mentally Challenged Children (CMCC) in Addis Ababa. The study specifically focused on the challenges, effects or consequences of challenges, coping strategies and specific needs and future perspectives of single mothers of children with intellectual disability. A phenomenological approach was used to explore the lived experience of single mothers and semi- structured interviews were applied with four single mothers of children with intellectual disability selected using purposive sampling technique. FGD and observation were also used for data collection. Findings indicated that death/separation of husbands, Family/societal reactions towards single motherhood as well as disability, lack of education /trainings for children with ID, lack of financial support and employment opportunity and uncertainty about the future are major care giving challenges of single mothers of children with ID. Results also revealed the effects/consequences of those challenges in mothers life such as psychological strains, emotional disturbance, social isolation, financial and spiritual crises. Hope, spiritual believes and develop relationship with other parents are also coping strategies mothers used. Moreover, the study indicated the mothers' wishes and aspirations such as access to access to diagnosis, referral as well as other health related services, teaching new generation about disability, developing education and training system for children with ID and creating integrated job opportunity for children with ID and their mothers. The findings expected to provide a detailed information and used as indicator of the need for further research on real life experiences of single mothers of children with intellectual disability not only in Addis Ababa but nationwide too. The results of this study also hoped to give insights and direction for researchers, educators, policy makers development planners and community leaders on what should be done in the future and take measures to minimize the lifelong challenges of single mothers of children with ID.

CHAPTER ONE

INTRODUCTION

1.1. Background of the study

Family is the one and the most important institute through which children satisfy their daily need of life and it also plays a significant role in children's holistic development. However, changes in family patters is becoming the influential factor to increase the number of single mothers all over the world and affects the entire family life. According to Kathryn A. Levine (2006), before 1950, death of spouse became the most common means of forming single parent family. In contrast, these days, separation, divorce or never married status are major contexts of forming single parenting. Divorce also become a global threat to families around the world including Ethiopia, (Rahel, 2014).

The number of families that are headed by single mothers significantly increased in the last three -four decades (Kathryn A. Levine (2006). The responsibility and role of single parenthood is mostly challenging particularly, when the woman is leading the family. Specially in Ethiopian context, where alternative child care systems are not developed, families, mainly mothers are the only sources support for their children's overall development (Rahel, 2014). Children living with single mothers have a home life that is differ from their peers living with both parents. According to Demographic and Health Survey of Ethiopia, (DHS,2011), majority of single mothers in Ethiopia are widowed or divorced. For poor single mothers, poverty-related stress includes worries to work, housing, food insecurity, discrimination, stigma, exposure to violence, victimization, and illness are some of the major problems that most mothers experienced in their day to day life. Studies revealed that most of single mothers are being challenged with no jobs or benefits are scarce, neighborhoods are deteriorated and unsafe, and community, family, and personal support are scarce (Cheeseman, 2010). In general, low-income single mothers are more likely vulnerable population than their married counterparts to suffer from mental and physical health disorders (Susan, Rose, Swaine, Dababnah, Marya & Lgdalsky, 2013; Rahel,2014).

These conditions are mostly true and even worse if a single mother has a child with disability. In Ethiopia, having a child with intellectual disability is still regarded as punishment for parents'

wrong doing and resulted feeling of shame on parents (Cherenet, 2000). Single mothers of children with disability have shared all challenges which all single mothers are passing through in addition to having a child with disability and its consequences. Misconception of a society regarding disability, lack of early identification and early intervention health related system and insecurity of their children's future life are some of major factors behind miserable life of single mothers of children with disability. Parenting a child with intellectual disability also extremely challenging for most of single mothers compared to parenting the non-disabled one. This research investigates lived experiences of single mothers of children with intellectual disability.

These days, disability is becoming a global agenda and gaining big concern of scholars, researchers, policy makers and many others. As a result, parents and children with disability in many developed countries are in a better condition compared to the last three-four decades (Huss, Olsson, Andersson, Granlund, Augustin, 2017). Due to change in attitude, advanced technology in medical treatment and services delivering, children with ID live longer and healthier comparing to the past. Moreover, the gradual change of the conditions in which these children are living with their family than in institutions highly contribute to their growth and development, (Heaman, 1995; Pelchat & Lefebvre, 2004). On the other hand, this change in favor of child's well-being creates number of problems in the family in which mothers are mainly affected by (Mackenzie, 2001; Pelchat et al. 2004). However, children with disability and their parents, particularly in developing country like Ethiopia, are living with ongoing challenges and practices. Parents, in many cases, single mothers of children with intellectual disability are one of those facing many problems due to number of factors related to raising a child with intellectual disability. In many cases, culture, religion, family environment, marital status (family structure) and employment are some of the factors influencing life of mothers of children with ID positively or negatively. Many studies conducted in the area revealed that having a child with intellectual disability is highly demanding condition in which many mothers particularly single ones pass through difficult lifelong situation (woldeab, 2007;)

According to McKenzie, McConkey & Adam, (2013), Intellectual disability, among other different types of disability, could be the largest impairment group in Africa. Findings from different studies revealed that the international prevalence of children with intellectual disability 1% to 3% of the world population is estimated of people with intellectual disability (Esdaile &

greenwood, 2003; Hassal, Rose, & McDonaid, 2005; Mabel, 2017). The presence of disabling factors and absence of prevention as well as intervention services in most of developing countries, including Ethiopia aggravated the increased incidence of disability (Tirusew, 1993).

In Ethiopia, data on prevalence of disability are mostly incomplete, contrast and focused on some disability areas like sensory disability, physical or intellectual disability (Tirusew,1995). According to the report of Housing and Population Census of Ethiopian Government, Central Statistics Authority (CSA, 1998), the number of persons with disabilities constitutes 1.9 % of the total population. On the other hand, the African Child Policy Forum (2011), in its overview of disability in Ethiopia, referred the 2007 census that estimated the prevalence of disability is 1.09%. However, this result is highly believed that the census under estimated or might not include homeless people, people with leprosy, epilepsy and children with intellectual or learning disabilities. Moreover, children with severe and multiple disability might not be include or being hide by parents because of fear of social stigma, isolation and discrimination.

The time when discovering that a new born child has disability is an event which is traumatic for most of parents particularly for the new single mothers. As the result, their immediate reaction may be negative and followed by a question “Why” which may last for many years, (Thwala, Kayi Ntinda, Halanze, 2015). Many parents particularly mothers of children with disability experience emotional and psychological disturbance that expressed with shock, self-blaming, depression, stress and refuse to accept the information about a child Thwala, et.al (2015).

Parenting children with disability is not only about full of responsibility which is expected in regular family life. It requires self-readiness and adjustment of life due to the presence of a child with disability in the family. The length of time, steps and coping mechanisms for reorganizing their lives defer from one parent to another depend on their knowledge about the problem, family pattern, support from the family, their socio-economic status, and accessibility of training, medical service and learning opportunity.

Some studies have reported that in many of African countries including Ethiopia, labeling a person with disability is still a common practice expressed by discrimination, stigma and isolation not only the children but also parents of children with disability. (Mabel,2017; Woldeab, 2007). Traditional beliefs and practices, socio economic factors, little or no knowledge

about causes of disability and lack of family as well as community support are some of the potential reasons to make life too challenging for children with disability and their parents. Poor medical and diagnosis services in early identification and intervention in addition to poor health and education policies and implementation system also have roles to make the situation more complicated. Little or no legal social security system and rehabilitation strategies also mentioned as factors having negative influences in the life of parents of children with disability.

According to a study conducted by Malhotra, Khan, and Bhatia (2012), parenting a child with intellectual disability highly requires the wellbeing of care givers particularly mothers. Mothers of children with intellectual disability mostly overwhelmed with a daily routine activities in order to fulfill their children's unique needs in relation to feeding, bathing, dressing, toileting, while fathers, as a bread winner, performing financial support. These huge indoor responsibilities due to their children's disability in addition to poor marital quality and co-parenting, lack of personal support network, little or no participation in social events and financial limitation put the mothers' life in danger. Single mothers of children with intellectual disability are those who lead the very poor quality of life (QOL) as a single mother and dealing with challenges related to the disability that may exist longer in their children' life (Malhotra et al.2012).

Even though number of studies have been conducted on challenges of parenting children with disability or/and parenting experiences of single mothers in general, researches particularly focused on the life of single mothers of children with intellectual disability in Ethiopian context are very limited and not in depth, (KG Agnail, et.al, 2017). Hence, the main purpose of this study is exploring the real-life experience of single mothers of children with intellectual disability in the case of Center for Mentally Challenged Children (CMCC) in Addis Ababa.

1.2. Problem Statement

Single mothers of children with intellectual disability face complex challenges and issues in their day to day life in connection to addressing the diverse needs of a child with disability and satisfying the entire family needs. In fact, both parents of a child with disability are expected to share responsibilities, burdens and successes in relation to caring for the child, many studies showed that still mothers are being vulnerable to several problems and paying as expensive as

their life in order to enable their children to survive through necessary clinical services and therapies, possible intervention of skill training and educational settings.

Apart from any mother who is always very close to and sensitive for the need of her child, single mother of a child with intellectual disability mean 'everything' to her child with countless responsibility because of nature of disability that her child is living with requires her full day special treatment in addition to the regular household management. All mentioned duties require mother's time, energy, emotional and psychological wellbeing, financial strength, flexibility and readiness to cope up the challenges.

At present time, many studies are focusing generally on the limitation of children with disability. Some others stress on the rights of PWDs such as educational policies like inclusion. Some also investigated care giver challenges and coping strategies...etc. However, there is also a need to understand the dynamics that exist in the life of mothers of children with disability and more specifically, the current study focused on the life of single mothers of children with ID.

The researcher has reasons to conduct this study focusing on exploring the lived experiences of single mothers of children with intellectual disability in CMCC. The major reason is observing many mothers of children with ID living with so many problems that put their life at risk. Many of them are economically very poor. Being weak physically with complicated health condition, feeling of helpless, regression and emotional disturbance and instability are some realities that one can easily observe from many of these mothers of children with ID.

Moreover, in condition in which the center is providing different trainings for their children, mainly focusing on daily living skills and some vocational trainings for children and mothers as well, many mothers are still looking stressed and unhealthy. Observing all these and some more difficult living situations of mothers encouraged the researcher to make an in-depth investigation specifically focused on real-life experience of single mothers of children with intellectual disability.

The study attempts to understand the deep-rooted factors behind the challenges of single mothers of children with intellectual disability from their own point of view which might have not been properly addressed before, and examining their ideas and wishes concerning perceived needs that should be addressed to make them healthy, happy and productive member of the society.

2. Objectives of the Study

2.1 General Objective

The general objective of this research is to explore and find out the real-life experiences of single mothers of children with intellectual disability with a focus on:

- investigation of the challenges and coping strategies and identifying future perspectives of mothers on addressing their specific needs.

2.2 Specific Objectives

The specific objectives of this study are to:

- identify the major challenges of single mothers of children with intellectual disability.
- investigating causes behind the challenges of single mothers of children with intellectual disability in their life.
- explore the influence/ consequences of challenges in health, economic, social, psychological, emotional, and spiritual aspects of lives of single mothers of children with intellectual disability.
- identify coping mechanisms of mothers.
- identify the current needs and future aspirations of single mothers of children with ID.

2.3 Research Questions

The following are the research questions of this study:

- What are the major challenges in the life of single mothers of children with intellectual disability?
- How do those challenges influence lives of single mothers of children with ID?
- What are the measures taken by single mothers of children with intellectual disability to cope up with the challenges?

- What are the specific (current needs) and future perspectives of single mothers of children with intellectual disability to have a better life with in their family, neighbors and community?

2.4 Significance of the Study

This study provides insight about the real-life experiences of single motherhood in raising a child with ID for humanitarian, policy makers and other stakeholders. Moreover, it will be used as extra inputs for development planners to modify and adapt the support system considering the perceived needs of the individuals. Above all, the result of this study will be significant to make a positive change in attitude of families, neighbors, teachers, health care professionals and communities at large towards disability and single motherhood of a child with ID and contribute their efforts for the better life of the targeted population.

2.5 Definition of Key Concepts

lived experience- refers to the experiences of single mothers in relation to caring their children with ID

Single motherhood- the word single motherhood used to describe a mother who is separated, divorced or widowed lives with and supports at least one child under 18 years of age.

Intellectual disability- is a type of disability characterized by significant limitations in intellectual functioning and in adaptive behavior and occur before age 18.

2.6 Organization of the Thesis

The thesis is organized in to six main chapters. The first chapter dealt with back ground of the study, statement of the problem, research questions objectives, significance of the study, limitations of the study and operational definitions of key concepts. The second chapter contained the literature review. Chapter three discussed about the research methods. The fourth chapter presented findings and chapter five dealt with discussion. The last chapter, chapter six presented summary, conclusion and recommendation.

CHAPTER TWO

REVIEW OF RELATED LITERATURE

This section presents the available and some empirical literatures more related to challenges that mothers of children with disability faced, causes of challenges, support systems and coping mechanisms used by mothers. However, literatures specifically on living experiences of single mother of children with ID are very rare. Moreover, the literatures which are available and closer to the current study are not in depth and in Ethiopian context. Most of them are highly expressive about mothers' life in raising children with disability, (no specification of marital status or nature of disability that their children were living in), others are about single mothers of children with disability, (no specification on the disability area). Only few study results are more related to the current study on exploring lived experiences of **single mothers of children with ID** and presented as follows.

Labeling a person with disability is still common in many places of Ethiopia including the capital city, Addis Ababa (Woldeab, 2006). People's general understanding of disability, particularly ID, still culture dominated and traditional practices also used to address the problem of individual with disability and their families. The Sociocultural or Ecological perspectives (Bronfenbrenner, 1979) is used to understand how parents, families and communities perceived causes of disability and how culture influence people's perception about disability. Thus, living experiences of single mothers in raising children with ID in current study also reviewed through mothers', families', and communities' specific understanding and expression about parenting children with ID.

2.1. Single Motherhood

A family comprising of a single mother or father having their own dependent children may be defined as a single parent family. According to Cariney, Boyle, Offord and Racine (2003), cited by Carbonari (2013), the word single motherhood used to describe a non-cohabitating never married, separated, divorced or widowed woman lives with and supports at least one child under 18 years of age. Despite the limited research on single motherhood, studies on premarital fertility, divorce and widowhood may be relatively high and possibly rising throughout Sub-

Saharan Africa (Gage-Brandon and Meekers; 1993, Garenne, Tollman and Kahn; 2000, Harwood- Lejeune; 2001, Rahel; 2014).

2.2. Intellectual Disability

Scholars used different version of definitions to intellectual disability. However, definitions that contained the three mandatory components mostly accepted and presented in many research areas. These three components which must be exist in the individual to define as having ID are; considerable limitation of adapting functioning, limitation of adapting behavior, in all its aspects, and the onset or occurrence of the disability before the age of 18 (Rubin & Divon, 2014).

2.3. Major Challenges of Single Mothers having Children with Intellectual Disability

The process of diagnosis of children with disability is often viewed as traumatic event for many parents which influences not only their health, emotion and behavior, but the entire life (O'Connell, O'Halloran, and Doody, 2013; Mercia, Fernandes, Alves, and Aguiar, 2016). The unexpected reality between Parents' hope and expectation to have a typical child and the newly born baby condition after diagnosis make dramatic changes in the family life. Many mothers use words like devastating, traumatic, emotional, overwhelmed and scary to express how they felt at a moment they know about condition in which their children are in (Melford, 2015).

Raising a child with disability is an experience which leaves parents with great stress and several caregiving challenges. Many mothers with this situation initially feel increased anxiety, sadness, emotional disturbance, isolation and depression (Cramm & Nieboer, 2011; Norlin & Broberg, 2013; Mabel, 2017).

Many research findings have shown that parenting children with special needs highly influences the whole family life in many ways. Long and short- term family plans, social life, work life, financial status, emotional and psychological well-being of parents are some of major aspects of life that could be primarily influenced by the existence of a child with disability in the family, (Ergu'n and Etem, 2012; Yildirim, Asilar and Karakurt, 2013).

Parenting a child with disability is demanding specially if the child is with intellectual disability, Autism spectrum, Attention Deficit Hyperactivity Disorder (ADHD) or with multiple disability (Mathilde and Lina, 2006). Some studies revealed that having a child with ID generates stress that affect the family members directly or indirectly and some of the main sources of stress also related to the nature and severity of disability and their significance to the family including social stigma and discrimination, (Patterson & Garwick, 1994; Pelchat & Lefebvre, 2004; woldeab 2007).

The interpretative study by Kearney & Griffin's (2001) aiming to explore the joy and challenges mothers based on semi-structured interview with six Australian parents of children with special needs found that, some mothers were mistreated by the health care providers focused on and mentioned the problems of the new born babies rather than congratulate them at birth and /or acknowledge the positive aspect of a child. Because of the existed attitudes and perceptions of disability, lack of acceptance and mistreatment from family members, friends, and health care professionals aggravate the psychological and emotional problems expressed by Anxiety, depression and stress, (Anjali, et al, 2017; Kearney & Griffin, 2001; Melford, 2015). expect hilling for their children.

2.3.1. Lack of Knowledge and Misunderstanding of Disability

Cultures and traditional practices are still powerful in governing society's perspectives on disability. Many mothers are overwhelmed in searching for the well-known traditional hillers and traveling long distance with additional financial crises whether the problem is addressed by or not (Kromberg, Zwane, Manga, Venter, Rosen and Christianson, 2000; woldeab, 2007). As it is clear and proved in different studies that the more early the problems identified, the better the treatment and prevention of other health related complications (Cerqueira et al, 2016; Dibakoane, 2016). However, different cultures and demographics also have their own role in parents' particularly mothers' understanding about nature and severity of the problem as well as actions they used to solve their children's problem. This in turn resulted negative out comes on mothers' effort to act for diagnose and intervention as early as possible and created extra factors to delay the child's holistic development as well as the way families understanding of disability (Dibakoane, 2016). All these are not only directly related to improving the situations of children with disability but also care givers, mainly mothers' smooth transition from shock and

uncertainty to be part of the solution by doing their best in caring of themselves and their children with disability.

2.3.2. Lack of Financial Support and Employment Opportunity

Economic problem is also mentioned as one of the major challenges faced by mothers of children with intellectual disability in number of studies (Ambikile & Outwater, 2012; Olsson & Hwang, 2008; Thawala', Ntinda', Hianze, 2015). Caring for children with disability can be more expensive comparing to caring a typical child as direct and indirect expenditure depend on the nature and severity of the disability, Dibakoane, (2016). Many mothers who have little or no income while their children with intellectual disability need intensive medical treatment, physical or speech therapy, special appliances with special educational and vocational services when many mothers are often not prepared for (Mabel, 2017; Thawala, et al, 2015).

The study aimed to examining the financial well-being of working mothers (18-64) of children with developmental disability compared to their counter parts of children with no developmental disability revealed that single mothers of children with ID experienced significantly worse financial challenges due to different expenses for special equipment and therapies, increased medical cost, reduced maternal employment and income and assets (Susan et al. 2013).

Henry (2017), conducted qualitative study with 21 participants to explore single mothers' experiences in raising their children in Chibolya, Zambia. Experiences of single mothers, their challenges and coping strategies were the three main questions that the study was aimed to address using thematic analysis. The result of this study revealed that single mothers mainly challenged with lack of job opportunities as they were poor in education and financial capacity. Moreover, these challenges deep rooted to poor families, friends, neighbors, and risk community surrounding them with no facilities to take care of children in absence of fathers. This condition makes the life of single mothers worse living in a community. Majority of mothers participated in this study were street vendors, janitors and engaged in risk behaviors. Researches conducted in comparing single mothers' financial problem with their married counter parts also have evidences that single mothers are living in lower economic status, higher level of stress and lack of sleep and leisure time (McLanahan and Booth, 1989; Sanik and Mauldin, 1986). In many cases, single mothers of children with disability are left by their partners and many of them do

not get any or little inconstant support from other family members or in most cases they do not get disability grant from the government due to weak or no social security policy.

2.3.3. Lack of Access and Affordable Service for Diagnosis

A phenomenology study by Melford (2015), aimed to explore the lived experiences of mothers of young children with special needs in rural setting indicated that though there were many challenges commonly faced by mothers living in both urban and rural areas, some key differences also emerged. Extra expenses, employment barriers, physical separation from their hospitalized infants, extra time devoted to travelling long distances and difficulties assessing peer support and information were identified as unique to their mothering experiences. All these are also highly considered as additional burdens that make the life of single mothers more complicated. A qualitative study on the experiences of mothers of children with ID in therapeutic itineraries revealed number of obstacles that mothers faced in searching accessible, affordable and sustainable services for their children as well as for themselves in relation to health, education and counseling, (Cerqueira et al. 2016).

Reports from similar studies also showed that mothers of children with ID experienced feelings of shock, denial, anger, negotiation, depression, and finally acceptance on discovering that their children are with ID through lengthy process of diagnosis (Esdaile & Greenwood, 2003; Ergu'n and Ertem, 2012) .

This is the most critical time for mothers when they seek the support of health professionals and institutions as they are un prepared to deal with and care for their children's condition. Whereas, the reality, according to some study findings, the challenges started from lack of communication in reception, lack of clarification and guidance about the diagnosis with slow referral system resulted mothers remain in doubt about the real condition that their children were in (Cerqueira et al. 2016; Melford, 2015). Lack of access to the needed early identification, intervention, rehabilitation, health care and other services are also the areas that are challenges of parents of children with ID (Inclusion International, 2006). Making diagnosis and health care services accessible and accept as well as respect the declaration of human rights help people with disability and their family are those raised as measures for better life people with ID in their community (Inclusion International, 2006).

2.3.4. Lack of Partners' Support and Poor Social Relationship

Marital quality and co-parenting have also a significant role in sense of wellbeing. According to Louis, (2014), the unfavorable conditions of mothers of children with intellectual disability in addition to poor relationship, lack of support from their partners, separation or death of partner resulting more stress and health complication in mothers' life. This in turn may influence the overall domains of life of both a child and mother. Single mothers are more vulnerable to severe stress, anxiety as well as depression than mothers living with their partners (Olsson & et. al;2001).

Findings on a systematic review on Quality of life of mothers having children with ID showed that both parents of children with disability have poor quality of life (QOL) but, mothers, in most cases, as they are the primary caregivers, become more affected by the challenges associated with daily base caring for their children with disability in addition to the regular family responsibility and satisfying the entire family needs (Anjali, Jose, Valsaraj, Nayak, Savitha, & Yashodharan, 2017). The study also indicated that the social relation domain was the major area which was negatively affected than other domains of QOL like financial wellbeing and family support.

2.4. Effects of Challenges

2.4.1. Un Healthy Psychological and Emotional State

Depression is one of the effects that mothers of children faced due to longer care giving challenges in their life (Aldersey, 2012; McNally & Mannan, 2013). The study conducted by Olsson & Hwang, (2001), in south west of Sweden aiming to assess parental depression in mothers and fathers of children with intellectual disability indicated that mothers of children with both ID and Autism had higher depression scores than mothers of children only with ID who in turn had higher scores than fathers of children with both disability areas as well as mothers and fathers of children without disability. The considerable longer time spent for extra care with practical work and devotedness mentioned as one of the reasons why mothers of children with ID are highly affected by the situation whereas fathers are less engaged in this responsibility

(Patterson & McCubbin, 1983; Roach, Orsmond, & Barrat, 1999; Mathilde Azar, et. al.2006; Anjali, et al; 2017).

Psychological and emotional states considered as dimensions of wellbeing indicators of one's Quality of Life(QOL). Attitudes and perceptions of people around parents including health care professionals towards single motherhood and having children with disability resulted unhealthy psychological and emotional state of single parents particularly single mothers of children with disability.

2.4.2. Weak Physical Health Condition

Mothers of children with intellectual disability mostly experienced deteriorated physical health, unhealthy psychological state, poor perception and interaction to the environment and restricted in social relationships (Anjali, et al ,2017). Feelings of loss (of a perfect or dreamed child and personal freedom), helplessness (not being able to change the situation and not get help when they need), and failure (not being able to peruse one's personal goals in life), easily fatigue, loose appetite are experiences of many mothers of children with disability (Olsson et al, 2001).

2.5. Coping Strategies

2.5.1. Family and Community Support

Mabel (2017), also revealed in his study aimed to explore the experiences of mothers in Ghanaian context that those mothers of children with intellectual disability are facing enormous challenges directly related to lifelong caregiving. Emotional reactions, perceived cause of disability, societal reactions, coping strategies they adopt to deal with their prevailing situation are major challenges mentioned by mothers participated in the study. Support from family or community, spiritual belief and hope are also reported as coping strategies that mothers used to cope up challenges. Moreover, the study reviled that mothers of children in this study were happy with the improvement and little achievement their children made so they didn't focus all the negative experiences rather they focused on the brighter side of their lives (Mabel, 2017). In some cases, limited materials from relatives and friends as informal networks and some little support like clothing, health care, materials and finance from Children International were mentioned as the coping strategies (Henry, 2017). Some of them also mentioned their views in

different studies that the financial support from family, society, and government and non-government agencies with high consideration of the specific needs of mothers will help them more to cover different expenses like transportation, medical and therapy care and special educational services.

2.5.2. Hope, Faith and Developing Relationship

Some study findings revealed that hope was found to influence parent's understanding of their children's condition and help them to navigate their emotional burden in anticipating the positive future for their children and provide them strength to cope with their challenges (Kearney & Griffin, 2001; Heiman, 2002; Kausar & Sobsey, 2003).

On the other hand, strong relationships and communication among parents with the support of other family members help more mothers feel not alone. This relationship fostered support on physical, emotional and psychological level, so became great source of strength for mothers of a child with disability (Mabel, 2017; Melford, 2015). Moreover, marital counseling services starting from the beginning of the challenges are highly recommended by many mothers of children with disability. Faith, hope and support from family members, spiritual beliefs in the form of prayers and organized religious activities are served as coping strategies for mother to overcome severe psychological problems in relation to having a child with intellectual disability Mabel, (2017). Number of studies also reported that strong support from spouses, siblings, grand parents, friends and professionals play significant role in mothers positive coping ability in alleviating stress and maintaining QOL.

2.6. Perceived Needs

A global report, on the living status of people with intellectual disability and their families revealed that 130 million people with intellectual disability and their families are in world and majority live in poverty (Inclusion International, 2006). The aim of this study was to awaken others to hear the voice of people with intellectual disability and their families. According to the report, regardless of the place where they live, people with ID and their families are the often-forgotten group in human life and invisible even in development and poverty reduction strategies. In the report, "Hear our Voice", people with ID and their families expressed their

ideas feelings and needs that didn't clearly understood by others. On conclusion of the report stated the general message of people with intellectual disability and their families as follows;

“We are people who have been identified as having an intellectual disability, and their families. We are mothers and fathers, sisters and brothers, aunts and uncles, cousins and nephews and grandchildren, grandmothers and grandfathers. We are children of parents who have an intellectual disability. We are friends and advocates who make a commitment to help advance full inclusion citizenship and human rights.

People with intellectual disabilities are neighbors and community members, school mate, co-workers and fellow citizen. As self-advocates and families, we call on others to recognize that we all learn in different ways and make our unique contributions to families and communities. We no longer want people to refer to “mentally retarded”, a term that has been used to devalue, segregate and discriminate against people. We all change those who would define intellectual disability as simply lower and deficient ways of remembering, thinking and communicating.

Our message is clear. Respect and understand differences. Value all people for their contributions. Treat all people with equality regardless of their disability, religious, gender, ethno-racial cultural, sexual orientation and other differences. this does not mean that people do not want to develop. On the contrary, we all want support to develop to our maximum potential and to pursue our unique life path. We all want to thrive with other members in our families, communities, schools and places of work. People with intellectual disabilities want the same”.

2.6.1. Policies, Laws and Practical Implementation

Caring of children with ID requires multi-disciplinary, inter disciplinary and inter sectoral actions to produce more effective response to the need of children with ID as well as for their parents particularly mothers (Cerqueira et al, 2016). Studies also suggested that strong policies and laws on disability with more practical implementation, enhancing the capacity and skills of health professionals to enable them to be ready to receive the children from the first moment to referrals and guidance with effective communication and care for these children and the mothers make the support more meaningful.

2.6.2. Information on Support Systems

Information regarding current and future support opportunities that a child or a family could be benefited from specially when the child gets older, (Huus et al. 2017). Some mothers also reported that their strong support needs related to time for themselves to read about others experiences and to meet other parents of children with disability. In some cases, parents of children with disabilities have common need of information, knowledge and skills regarding child development, child disability and handling behavior problems (Bailey, Bruder, Hebbeler, Carta, Defosset, Greenwood, Kahn, Mallik, Markowitz, and Spiker, 2006). Parents who report having their perceived need like knowledge, skills and available support services are more likely to exhibit strong self -confidence in their ability handling problems related to their children (Huss et al. 2017).

2.6.3. Guidance and Counseling

Studies indicated that addressing psychological needs of mothers like guidance and counseling on the health status of their child as well as how to look after them from the moment of birth should be considered as a means of more humanized and comprehensive care to ensure the right of individuals with disability and the entire family (Cerqueira et al, 2016). Mothers, as they are vulnerable for number of crises in relation to caring their children with disability in addition to other responsibilities, no doubt about the importance of guidance and counseling service. Timing and continuity of delivering the service by professionals also makes big difference on the psychological wellbeing of mothers of children with disability. This in turn plays a significant role in their acceptance of and dealing with the situation.

2.6.4. consideration of Family Needs in Support System

Although different supports and coping mechanisms have been mentioned in many studies, the limitation of considering the specific need of those mothers in addressing their problem are still existed. The study conducted by Woldeab, (2007), reviled the specific needs expressed by parents of children with intellectual disability including need for information about their children disability, need for social support, need for vocational trainings for their children and for

themselves, access to Medical services with continuous psychological support before and after diagnosis.

Similar ideas also recommended by many mothers in some studies as major solutions to minimize their burden. Huss, Olsson, Andersson, Granlund, Augustine, (2017) have conducted the study in Sweden aiming to investigate the perceived family needs of parents of children with mild ID and to investigate the relationship between parents' self-efficacy in their parental role and in collaborating with professionals as well as with their perceived need for support conducting interviews with 38 parents of children with MID, revealed that the specific needs of these families are related to information and skills regarding adapting home environment in order to address the special cognitive needs of a child and to handle the behavior problems.

O'Connell, O'Halloran and Doody, (2013), wrote an article on 'Raising a child with disability and dealing with life events: A mother's journey'. A single mother of a child with developmental disability is one of the authors supported by a nurse and an academic professional. The authors explained that working with families or single parents, particularly mothers of children with disability need extreme openness of the professionals considering a two-way process that enable the mothers feel listened by and no longer invisible.

Recognizing the importance of effective communication when dealing with mothers of children with disability highly assists professionals' effort to understand the perceived needs of a mother working as partnership and to co-ordinate supports accordingly. Moreover, the authors explained that nature and level of support for parents should be specific and address the need of the family as well as the child with disability (O'Connell et al, 2013).

Other studies also mentioned the importance of effective communication and partnership approaches not only between parents of children with disability and professionals but also between professionals to make the services more effective (O'Halloran and Doody, 2013; Maxwell and Barr, 2003).

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

In this chapter, detailed description of the research methodology that was utilized in this study will be discussed. The chapter is organized in sections used to provide detailed description of the research procedures. Description of the research area and study design, followed by other components of the method, data sources, sampling strategy, study population, data gathering techniques, data analysis and ethical consideration will be presented as follows.

3.1. Research Design

This study followed a qualitative research design. The qualitative research design defined in various ways by different scholars. Strauss and Corbin (1988), defined qualitative research as a study design best to explore individuals' life, behaviors, emotions, feelings, lived experiences as well as cultural phenomenon, social movements and organizational functioning.

The qualitative research approach helps the researcher to study nature of phenomenon by understanding the participants point of view (De Vos, Strydom, Fouche, & Delport, 2011). Phenomenology a philosophical approach to explore views of people's individual experiences in particular area although the views do not to be generalizable, they do offer a depth in to the lived experiences of individuals (Fulcher and Scott, 2007). The main purpose of phenomenological research seeks reality from individuals' narratives about their experiences and feelings, and providing an in-depth description of the phenomenon (Smith & Osborn, 2003).

Pelin Yuksel & Soner Yildirim (2015), stated that the aim of phenomenological research is describing a specific phenomenon in-depth and reach at the essence of participants' lived experiences of the phenomenon. According to Streubert and Carpenter (2002), this research method is demanding, critical and systematic. The researcher also used the phenomenological research design for this study which explains lived experiences of single mothers of children with Intellectual Disability and excludes the researcher's opinion.

3.2. Research Area

3.2.1. Brief Description about the Center for Mentally Challenged Children (CMCC).

In Ethiopia, as most of African countries, children with disability and their parents are disadvantaged and marginalized in many ways. Lack of awareness, traditional practices, culture and religion have predominantly influence community's attitude towards disability. These in-turn resulted misunderstanding and mistreating of children as well as parents of children with disability.

With this background, the Ethiopian Evangelical Church Mekane Yesus (EECMY) adopted educational program for children with disability and support system to their parents in its Child and Youth Care Program (CYCP). This contributed to the foundation of a center for children with ID in 1986 with the support of concerned international partner organization Kindernothilfe (KNH).

Ms.Doris Bornhausern, from Germany, started the program around Kazanches with one child whose name was Tariku (true name). In 1995, the center has been well organized and built its own training center around Mekanissa near to German Square while the first one still working in Kazanches. The center is under the supervision of Ethiopian Evangelical Church Mekane Yesus-Development and Social Service Commission- Education Child and Youth Care Program (EECMY-DASSC-ECYCP).

At present, CMCC is supporting around 400 children in different programs in both locations to achieve the objective of a center that is improving the life of children with ID and minimizing burdens of parents, mainly mothers'. Children with ID are getting different services in different levels based on their age and severity of the problem. **Early care, pre-group, Montessori, pre-vocational and Life and Work Skill Training** are classes where children are attending their education and trainings. **Home visit, Saturday and Guest students' programs** also extra opportunities providing for those who couldn't get a chance to attend trainings in regular base. In addition to working on awareness creation and different trainings for mothers related to dealing

with their children's situations on how to start petty trade in their surroundings. Although the center is getting different support from partners, there are also constraints affecting the expansion and improvement of services that the center is delivering. Lack of community awareness, financial limitation, lack of transport facility for younger children and shortage of trained and interested human capital in the field are main challenges of the center. Currently, the center has professional coordinator and assistant coordinator, 30 teachers who are well trained with rich experiences in teaching and giving trainings for children with ID and their parents. There are also 12 non-teaching (supportive) staff and 8 youths with ID (former trainee, now employee). CMCC is the specific research area for this study where the researcher conducted the study.

3.3 Sampling Strategy

Purposive sampling was used to recruit a sample of mothers to gain an in-depth and rich experiences of mothering children with ID. Morse (1991), defines this method as a strategy used to select the participants based on their ability to provide rich information about their lived experiences. According to Grinnell and Unrea (2008), this type of sampling does not depend on the views of the researcher rather the characteristics that best fit to the significance of the study.

The sampling process basically considered three main eligibility criteria. Biological mother, single mother and having a child with ID from the age of 15-20 years were the specific target group of this study and 4 mothers were purposively selected from the special school "Center for Mentally Challenged Children" (CMCC) in which their children are getting training in three different vocational classes. The purpose of this eligibility criteria was necessary to focus on mothers' life who had longer journey in caring for their children with ID from infancy/initial diagnosis to the present.

As researches suggested that adaptation rates were variable and adaptation was not inevitable (Amato, 2000; Lucas, 2005), the length of time as a single mother is considered and used as one of the eligibility criteria in the study. Moreover, as a study aimed to focus on the life of single mothers and a sole adult in the household, role overload to be a significant strain predictor (D'Ercole, 1988), all participant mothers are single, two are widows and separation was the case for the other two mothers resulted from having a child with disability.

Initially recruitment proceeded through calling to the coordinator of the center and scheduled the day to present the purpose of the study, then I have been two days to meet the coordinators and teachers to present the purpose of the study and the reason why I wanted (choose) the center to conduct study in. I have also presented the letter from the Addis Ababa University for the coordinator then finally I gave clear eligibility criteria of the study for teaching and supportive staff in the center who had full information about the parents of children with ID in the center. The letters of information contained the researcher's contact were given to teachers who were giving trainings in three vocational classes to distribute for best fitted participants. This method was chosen for better clarification of aim of the research and to ensure the confidentiality of information gaining from participants it was also used to build trust between the researcher and mothers through the entire study.

The sample size is determined by the nature of interpretative phenomenological study basically depend on the quality and richness of the data. Thus, the researcher decided to make an in-depth exploration on the life of 4 single mothers of children with ID which indicated the researcher's judgement on the quality of the data (Sandelowski, 1995).

3.4 Sources of Data

As it is an in-depth investigation of mothers' life, the main sources of the data of this study have been Single mothers who have children with intellectual disability. Among them two mothers have two children including one with disability the other two are having a child with ID. These mothers are specifically selected considering their children's age (above 15), and duration in the center (more than 5 years) in getting different services for their children and themselves in the Center for Mentally Challenged Children (CMCC). Assistant coordinator of the center, social worker, senior teachers and non-teaching staff in the center also participated in the study to get their view concerning the life of single mothers of children with ID.

3.5 Data Gathering Methods

Semi-structured interview with open ended questions has been used to identify lived experiences including major challenges, influences of challenges, coping strategies, perceived needs and future perspectives of single mothers of children with ID (Appendix A). Based on all participants' preference interviews were conducted in the one of the conference room in the

center. The interviews were recorded with the mothers' permission and lasted between 50 minutes to an hour and forty-five minutes. Interviews were also informal in nature and conversational to allow for open dialogue. This approach provided flexibility and openness at the time of face to face interview takes place. I started the interview by raising the general question: Tell me about your life before getting birth of your child (insert name of a child). prompts also used to encourage the participants for more sharing of their lived experiences. Demographic data including educational, marital and employment status of mothers, age of their children with intellectual disability, type and severity of the disability (when available on the diagnoses result paper) were gathered from the participant at the beginning of the interview (Appendix B). Field notes also taken as soon as possible after the interviews to make sure that all observed explanations were recorded in a timely manner (Patton, 2002). Direct observation on mother-child and mother-teacher interaction also used to gather sufficient information that how these mothers could deal with their children and others in different situation. During data analysis, I was reading and rereading the transcripts to familiarizing the data, generating initial codes, searching and revising themes and defining and naming themes. I also had a phone call interview with one mother and physically with the other three to share my interpretations to ensure whether I had correctly captured their lived experiences or not and also invited them to provide any other impute they might want to add on. Extra information, specifically about the life of single mothers from FGD of Senior teachers who are rich in many years of experiences in giving trainings for children and counseling mothers and currently teaching the children whose mothers are participating in the study also included.

Reports and files from the center related to the child or/and a mother have been considered as extra sources of data. Moreover, the information regarding what and how the center works with mothers of children with ID included. These details have been gathered by having interviews with the coordinator and senior teachers in the center. Before conducting the actual interview, FGD and key informant interview, all the questions have been reviewed together with friends and senior graduates and the researcher's advisor to make sure the questions are clear and appropriate.

3.6 Method of Data Analysis

Since the study is phenomenological with its general purpose to understand and describe a specific phenomenon in-depth and reach at the essence of participants' lived experience, the analysis has been done using the principles of Interpretive Phenomenological Analysis (IPA), which basically deals with examining how people make sense of their experiences (Smith & Osborn, 2003). The aim of phenomenological analysis is uncovering the themes that help the researcher to describe the reality behind individuals' life (Van Manen, 1997). According to Larkin, Watts and Clifton (2006), IPA as a combination of interpretation that concerns the experience of participants considering their culture, social environment and hypothesis whether their psychological framework has been influenced by the world system or not whereas, phenomenology is concerned with explaining on how the participants understand a certain phenomenon and the way they understand themselves in the real world.

Thus, data analysis has been done following the four major steps, (a) familiarization with the data, (b) generating initial codes and searching for major themes, (c) reviewing themes, and (d) defining and naming themes.

3.7 Ethical Considerations

The researcher was providing a formal letter for the center of mentally challenged children by acquiring from the department of special needs education Addis Ababa University to approach parents, teachers and administrators in the center. The rule of thumb for confidentiality applied during the time of the interview with mothers, teachers, social workers and center administrator. The researcher was taking note and voice recording after collecting the written or verbal consent from the participants. Participants were brief about the aim of the study and they were informed that all the information they were given will be confidential. During the interviews, the participants were assured that they didn't have to share anything or answer any questions that made them uncomfortable. They were also told they can withdraw from the study any time they want to.

3.7.1 Informed Consent

The researcher explained the aim of the research and gave the Participant Information Sheet (PIS) to participants with necessary details. The consent paper also given to participants and explained by the researcher to avoid any misunderstanding. They also encouraged to ask any questions not clearly explained before signing the paper.

3.7.2 Anonymity

According to Babbie (2010), anonymity is attained when people cannot recognize responses given in a research study. It also means the participants are anonymous. (Newman & Krueger, 2005). To ensure anonymity, pseudonyms were substituted for participants' and children's names. All the information shared during the interviews also kept anonymous.

3.7.3 Confidentiality

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

3.7.4 Privacy

According to De Vos et al, (2011) Privacy is about to keep to oneself that which is normally not intended for others to observe or analyze. Privacy was insured since interviews were conducted in closed room and no one was there except the researcher and the single mother on their own preferred schedule for place and date. Each of the participant mothers were free to express themselves and explaining their life including all the past and current and the future too.

3.7.5 Storage of Data and Access to Results

The data were stored in locked cabinet in my home and password protected on my computer. Participant identifiers were kept separate from audio records and typed transcripts so that they are disclosed in any publication or presentation of findings. The transcripts will be accessible only for the researcher's supervisor and the theses committee.

3.8 Self- Reflectivity and Avoiding Bias

Self-reflectivity is an important tool in qualitative research pillow (2003). Throughout the process of data collection, the researcher had to self-reflect and being critically and explicitly conscious of what she was doing in the research study. She did her best to eliminate or avoid bias by not being guided by her own judgment. After each interview, she had reflection on the interview with the participants to normalize the situations where the participants became emotional. Responses depended on how much detailed information had the researcher gained about the questions. Honesty was maintained during sharing insight and information with the participants. The researcher made sure that the results were accurate and dependable whereas clarifying that it could not be generalized to the entire population rather focused on the single mothers of children with ID participated in the study.

CHAPTER FOUR

FINDINGS AND DATA PRESENTATION

4.1. Introduction

This chapter contains all the presentation and discussion of findings from the data collected in the study on the lived experiences of single mothers of children with ID. The researcher could gain insight about the phenomena using Interpretive Phenomenological Analysis (IPA). The chapter begins with a description of the study participants and proceeds to discussion and findings identified using coding the major and sub themes.

4.2. Brief Descriptions of Participants

This section provides a summary of each participant's significant life events and demographic information. The researcher believes that this will enable the readers to have clear understanding and complete picture of participants generally as women, mothers, single mothers, and particularly, as single mothers of children with ID. The participants are categorized in two sets based on the pathway they became single mothers. These are death of husbands, in the case of two mothers and, separation on the other two mothers.

Asnakech, Beza's mother;

Asnakech was born in a small town about 300 km to north from Addis. She was 9 when she came to Addis Ababa to live with her niece because of her parents' death. Now she is in her 39. She stopped her school from grade 4. When she was 15, she started relationship with her friend and decided to live together as husband and wife. She was 17 years old when she got birth of her baby at home with no medical checkup before, during and after birth. Asnakeche's husband died by accident when her baby girl was 7 months old. Since then, she is leading extremely challenging life working as a daily laborer. Though she knew that her child was so weak and delayed in her overall development compared to her agemates, she had no idea that her child is with ID until the child reached 8 years old. She used to go to some well-known persons called "Awaki" in the area as old women advised her to go and obey what these wise people ordered to

do certain things to make her child healthy, and the mother did all. Her daughter was 8 when Asnakech went to hospital for diagnosis after she got the information from an individual who knows families of a child with ID. Now her daughter is 19 years old and she is in her last year of getting skill training in the center joined when she was 10.

Birke, Sisay's mother;

Birke was born in southern part of Ethiopia. Birke was 13 years old when she came to Addis Ababa to live with and serve as a baby sitter to her older brother's baby boy. Two years later, Birke couldn't agree with her brother's wife, and has started to work as a maid in other family and got 50 Birr per month. She also had a chance to go to school at night and reached grade 6. When she was 20 she has mate a guy, who was a driver in a government organization. He was also a field worker and may stay longer from 3-4 months. Soon they decided to live together and Birke got birth of her first child, Sisay. Two years later she got second baby boy, Alemayehu, and when he was 11 months, Birke's husband has been severely sick and after 4 months suffering, he died from HIV. She didn't have any idea about that since the virus made her too weak. A year after Birke got sick and stayed in hospital for about a month and informed that she is a victim of HIV AIDS and she is living with. Although Birke took her son (Sisay) to government hospitals and clinics as she was suspecting that something was wrong with him observing some unique behavior compared to his younger brother, no one told her that he is a child with ID. He was too slow in his cognitive development and self-help skills like eating, dressing and toileting, He showed in delay in speech till he was 12 years old. Birke used to go to her husband's homeland with her sister in law to find the solution from traditional hiller in the family. But nothing has changed. Finally, when her son got seizure, she took him to Hospital and got information about the real condition of her child. Now Birke is helping herself and her children by selling charcoal near to her house and sometimes washing clothes. Because she uncovered her health condition to the community, people especially youths highly support her and her children in many ways. At present, Alemayehu, the younger son, is a 1st year student in the university.

Meskerem, Daniel's mother

Meskerem was born in Addis Ababa. When she was 15, her father died and she dropped her education from grade 8. She was helping her mother in her small business at home (selling Enjera), then she started working in one foreigner family house. She was getting a better monthly salary with some benefits. After 2 years, she mates a guy who was working there as a guard and decided to live together as husband and wife. After 3 happiest years together, Meskerem got pregnant and because she had untreated STD, she has been forced to have a baby boy when he was 7 months. Soon, when he noticed that the child was not healthy, her husband left her alone by giving her a reason that he was going to find some financial help from his family in countryside far from Addis. Since that day, she heard a lot about him but she couldn't see him. Family and societal feedback for her being single mother of a child with ID, lack of employment opportunity and being cheated by her husband hurt her more than caring her child with disability. The result of her child's diagnosis showed that he is with "mild intellectual disability". He is attending the training in the center for the last 8 years.

Belaynesh, Hanna's mother

Belaynesh was 15 years old when she came to Addis Ababa before 23 years because of her mother's death. After 5 years of working with one family as maid, she decided to start small business to change her individual life. That was a time when she became pregnant of her child from a person who promised to marry her and disappeared after he noticed that she was pregnant. Later she knew that he was married and had 3 children. After two days of hard labor, she got birth of her child in a clinic. She was going to the same clinic for vaccination and other services but no one told her that her child is with Intellectual disability. Though Belaynesh was doing her best for her child, she was also noticed that her child was slow in speech, walking and other activities. When her child became 5 years, Belaynesh mate one guy who was supporting in some expenses so they started to live together as husband and wife. After two years she got birth of the 2nd baby girl. A year after, Belaynesh decided to live as single mother because her husband didn't treat her older daughter like the younger one. Moreover, he was mentioned that her daughter was a result of her sin as she slept with a married person. As a result, Belaynesh couldn't tolerate him and decided to live alone with her two children. Her child couldn't speak clearly at age eight. Hence, she took her to hospital where her daughter was diagnosed for ID. Now Belaynesh is living with her daughters, one with ID and the younger one is 5th grade

4.3. Findings

During the interview session, number of issues related to lived experiences of single mothers of children with ID were discussed. The issues were considered to address the research questions and mainly related to what challenges mothers faced, what did they do to cope up challenges, and what do mothers say about what would be done in the future.

Analysis of the interview transcripts yielded five major themes that best captured the experiences of mothers raising a child with ID. The themes were categorized in to major and sub-themes. Each major and sub-theme was described and supported by direct quotes from the interviews. The major and sub- themes are illustrated in table 1.

Table 1. Themes and Sub-Themes with Short Description

Themes	Sub-themes	Description
Journey to the unexpected reality	<ul style="list-style-type: none"> - Traditional practices -Medical treatment -Information from individuals 	This theme focuses on the ways that mothers passed by till they get information what ID is and where they should go for services.
Major care giving challenges	<ul style="list-style-type: none"> - Death / separation of Partner or husband - Family / societal reactions - Lack of education and training - Lack of financial support and employment opportunity - Uncertainty about the future 	This theme is all about main problems that mothers faced in relation to caring of their children with ID.
Consequences of care giving challenges	<ul style="list-style-type: none"> - Psychological strain - Emotional disturbance - Social isolation - Financial crises - Spiritual crises 	This theme explains how QOL of single mothers influenced by the challenge raised from caregiving a child with ID.

Coping Strategies	<ul style="list-style-type: none"> - Spiritual believes - Hope (better future) - develop relationships with other parents in CMCC 	This theme mainly focuses on measures taken by mothers in dealing with and cope up the situation to support their children as well as themselves.
Mothers' future wishes and Aspirations	<ul style="list-style-type: none"> - Access to diagnosis, referral and other health care related services (for new mothers) - Teaching new generation about disability, - Developing education and training system for single mothers and their children with ID - Creating integrated job opportunity for children with ID with mothers - Stablishing working and living environment for orphan children with ID 	This theme contained the perspectives of mothers on what should be done in the future based on their passed life experiences, their current specific needs and the future support system for both mothers and children with ID.

4.3.1 Journey to The Unexpected Reality

These theme is all about the mothers' effort to understand the situation and addressing the need of their children with ID. All participants in this study mentioned that they passed through extreme difficult situations in getting even what was their children's problem exactly. The unconditional motherhood love in addition to being exclusive parent forced these mothers to try any means, in most cases which never solve their children's problem rather make their life unstable and full of stress. In addition to the mothers' physical well-being and mental readiness, this journey also highly required time, money and family support thought none of the participants have fulfill these conditions. Traditional practices, medical diagnosis, personal knowledge and individual's information were mainly considered as measures taken by mothers in relation to understand the reality and seeking to solution for their children with ID. They express their feelings considering the above idea as following;

a) Traditional Ways

Belaynesh- *“... it was not easy for me to understand my child’s problem so I did some traditional practices based on advices I got from senior mothers and other people who used to practice as the solution for different problems they faced in their family life”.*

Asnakech – *“I used to go everywhere that people told me to go and obeyed every rule to do so, though that changed nothing in my child’s condition except make me obsessed and being restless”.*

Birke – *“Since I got birth, I was looking for and running to the “real hiller”. Everyone told me that I must go here and there, and you know?... I did everything that neither me nor my child could get benefit from. The only thing I got was lost of money and my energy even to carry on my child”.*

b) Medical Diagnosis

Medical diagnosis is the other way that single mothers of children participated in this research used to know their children’s real condition as well as appropriate services. They also explained that the service was not easily available and the process was so exhaustive which required finance, time, energy as well as psychological and emotional readiness of mothers’.

Meskerem – *“Though I used to go from one clinic to another including big Hospitals, no one told me exactly what the problem except I had prescriptions for some examinations and medicines. Finally, a Doctor in government hospital directed me to another hospital to get service for diagnosis and then they told me that my child is with ID. But ... You know..., it was not easy ... specially for me to understand what ID really mean ...I mean ...I didn’t get it was clearly explained by the health care professionals as it will be the life-long problem ...”*

Belaynesh *“... Although it was too late, I took time in hospitals to find out why my child was like that. It took long process for diagnosis, ... and It was a big problem for me to waiting months to know what it was, ... to go from one hospital to another. Not only that, because too much information I was getting from individuals, professionals, and others, ... like traditional hillers*

that I visited, it was completely difficult for me to understand which information was right and work on it.”

c) Information from Individuals

All mothers agreed in one common idea that they couldn't get clear information and directions from health professionals. On the other hand, some individuals including taxi driver, daily laborer, youth group on the street, a teacher and a mother of a child with ID play great role as sources of information that helped mothers more to have ideas about ID. Moreover, this information directed mothers to the center in which their children and themselves have been benefited in one way or another. When mothers expressed this;

Birke- *“A teacher in one private school told me about the diagnosis service in Black Lion Hospital so I went there”.*

Belaynesh- *“I didn't know that I have to go to hospital for diagnosis since a taxi driver told me to go and get access for services in the center. ... I wonder why other medical people didn't inform me to do so while I was there to other medical issues of my child...”*

Asnakech- *“A person who was working with me in a daily labor informed me that he saw children like mine on the way to the center so I found the place and then teachers told me where I have to go for diagnosis ... yah”.*

4.3.2 Major Care Giving Challenges

This theme mainly discusses the general objective of this study. Participants revealed the major challenges that they experienced in their life since they got birth of a child with ID. Death or separation of partner/ husband, family and societal reaction, lack of integrated diagnosis and referral system, and uncertainty and extreme stress on futurity were mentioned as major problems.

a) Death or Separation of Partner

For some individuals being a single parent might be the issue of preference which didn't happen in the case of all participants in this study. Separation and death of husbands were the two well-known path ways in which the participants in this study became single mothers. All the participants in this study highly considered this incident as the starting points to their lifelong challenges. Mothers mentioned that the death or separation of husband/partner severely affected their dream and futurity. For these mothers, lack of psychological support and social values sound loudly more than lack of financial benefit from their husbands. In the case of two single mothers in this study, death of husband in the first two years of and lack of his presence make their life too hard to be adjustable. They stated;

Asnakech - *“My husband was the only one that I could count on for everything, ... he was so thoughtful and honest. So... when he died by accident, I felt like I was insecure and totally lost power to restart my life. To be honest, I don't think that I suffer this much if he were in life.*

Birke- *“Although he was the cause for my sickness, I wish he could be alive with me and with our children. I think that would be so meaningful. we might be in a better condition if my husband is alive no matter how our health condition would be severed, we could support each other for the sake of our children specially for Sammy (one with ID).*

In the case of other participants, separation, as one path way to single motherhood, created many problems which influence the whole family life. This is a serious issue particularly in a society viewing single motherhood as unwanted, weak and unprotected. These mothers even believed that societal attitude towards a woman having a child with disability has been the reason caused their husbands disappeared and left both mothers of children with disability vulnerable for unexpected psychological problems as well as social isolation. Mothers in this case expressed their feelings

Meskerem - *I got sick when I realized that my partner left me alone specially at that time when our child has been in hospital as he was born prematurely. I sometimes think that my husband might be afraid of being a father of a disabled child or a husband of a woman who got birth of unhealthy child. Yah... who knows? You know... I tried my best to adapt myself with my child's*

situation but could not tolerate the way people approach me unfairly and misunderstand my life as being left by a husband because of having a child with ID.

Belaynesh- I remember that people around me mentioned the issue of my partner and me which was not true. So, it was the reason that forced me to be isolated from any social gathering. I was hearted more by this situation than being left by him as he was a married one that I didn't know about.

b) Family/ Societal Reactions Towards Disability

Participants in this study repeatedly mentioned that misunderstanding of the community towards disability is highly aggravating the existed unfavorable living conditions of both children with ID and their single mothers. These single mothers also explained that how discrimination and stigma even in their own family forced them and their children being isolated from most of the events in which they had great role before. They also stated their experiences about the situation;

Meskerem - You know what? I ... might tolerate what others said about me and my child, but, my mother, even she couldn't understand me and my child! Oh...God!!! She believes and says it now and then that God gave me the disabled child to punished me for my sin not to ask her willing to live with my partner. Whenever she mentions about this... with hard words.... Oh...God! I'm living in her home since my partner disappear, so this is her evidence that she used even to warned other youth in the family. Though I'm the one who cover every expense for living as the only child for my mother, she always says that I'm privileged by living in her house with my "Sick" child. Yah.... It seems that.... but, I prefer to live in the street than living in that home killed by my own mother day by day morally, and psychologically.

Birke- "Most of the time people laughing at my child's action or the way he talks, then they showed different signs which represent asking God excuse not to make them like my child and/or not give them the same child as mine. They don't have any idea about the implication of their action in my mind. It tells me a lot about how people are still in bad thinking about disability and living with traditional believes whether they are literate or illiterate. Dealing with this unchanged situation every day makes me so weak and hopeless."

Asnakech- *In most cases I observed that people tried to treat me in a special way as if I myself also disabled like my daughter with ID. Moreover, I couldn't tolerate the way people stare at me and my daughter when we go to the center and back to home. The same thing happens in transportation, at church, in the market...everywhere! And ... yah...I became very aggressive and sometimes screaming and telling them that we are human beings like them no other creation*

Belaynesh- *I wonder why people in Addis Ababa, a big city, couldn't be changed in their understanding about disability. I thought that people in country side, like in my home land, might have negative attitude about and that is why I couldn't return there with my daughter. But here, ... every day on my way to-from the center with my daughter, people showing their sympathy by seeping their lips.... what does that mean? I think it means they feel sorry for me and my daughter. Why...? because they think that we are punished or cursed. Currently, even me and my younger daughter could understand and teach others that neither me nor my child is a symbol for God's punishment or being cursed".*

c) Poor Diagnosis and Referral System

This theme discusses the challenges that single mothers in this study faced during the process of diagnosis and related services in health care centers. According to the participants, the long process with lack of clear information about what is going on, poor documentation, and Poor communication skill with un ethical approaches also mentioned as problems that these mothers faced in some health care centers. Moreover, mothers complained about poor referral system meaning too late or not to the right place with different prescriptions for some unnecessary checkups and lab tests. They explained these;

Belaynesh- *I was so upset when I was asked to tell them the history of my child for the 4th time in hospital where I was getting vaccination and other services after I got birth. I was there to hear the result not as a new comer. And, I think ... oh yah...I shouted at them then the one, ... who was a kind of boss for nurses told me to go and not to come back again. I remember, that was the first day I wished to kill my child and myself on the way to home. Of course, they might know nothing how I was in so many problems alone with my poor child, how I was going there every week by foot caring my child, in need of some information about my child condition. Anyways,*

since that day I gave up and turned my face to traditional practices which also didn't work either... till I came back to medical treatment with the help of teachers in the center

Meskerem- I went to hospital for diagnosis when my child was almost two years old. The Doctor asked me very few questions, ... hum I don't think that he could even listen to my replay, he gave me prescription for medicines and to have test (stool, blood and... other, which I forget now). He also told me that my child will be "OK" and will have follow up every month. I couldn't get a chance to ask any question. The medicine was vitamin so I think it helped my child but I didn't understand why blood, stool and similar tests? Next month, I couldn't find the previous one. So, I told the new Doctor every detailed about my child's problem. Surprisingly, he prescribed the same tests and told him I already did all thatI was so hot..., but he was so polite and respectful. Finally, after two more weeks in observing the child's behavior and related issues, he informed me what he suspected about my child that he might be with a kind of "mental problem" that could be checked by another Doctor in a private clinic. I went there but must wait 4 months to see the Doctor since there was long waiting list. Besides, it was too expensive specially for a person like me you know ...? Anyways, when the time reached, I remember ... it was a rainy season in which I even couldn't get labor work, then I had a gold neckless, the last thing I could use, so I sold it and payed the money for diagnosis.

Birke "... I only remember that the doctor told me to go to 'Amanuel Hospital' to have a medicine for my child and I was extremely worried that I thought, ... my child was out of mind, ... mad! But the medicine was for the seizure not madness !!!".

d) Lack of Financial Support and Job Opportunity

This theme is focuses on other care giving challenges that the participants facing in their entire life. Finance and employment are the two interdependent issues having cause-effect relationship. Having a child with ID and looking for employment is completely challenging for many mothers in developing countries like Ethiopia where gender inequality, political instability, poverty and lack of awareness towards disability are still existed predominantly. No one of the participants in this study are workers neither in a government nor in NGOs. They also don't have monthly income from any sources except daily labor work income which is not always available. This indicated that these mothers are highly depend on their own daily income to cover their daily

expenses. On the other hand, they need more money for other unexpected expenditure related to caring their children with ID than for daily living costs. They express this problem as follows;

Birke - My child has additional untreated problem on controlling the urine. In keeping his personal hygiene, I need to buy a soap in every 2 days and enough water otherwise I can't take him to the center. Look ... my hands, ... it's impossible to stay for two days without washing his clothes, so I need extra money even for a soap in every two days. If I feel tired or sick and couldn't go out to wash clothes or cleaning even for two days, it would be a big problem as no one considered this and tried to fill the gap. I don't know how far I go with this situation ... because I'm really feeling tired ...as I am living with the virus, working outside and taking care of my child at home... it's truly hard. I am not getting any financial support from government except free medicine to myself.

Asnakech - "I'm working hard the whole day whenever I could get a labor work, but the problem is the money which I'm getting is not enough to cover all my expense and Sometimes I might get some money from people who considered my problem but not in a regular base so I save that to my child that, ... I'm afraid that one day, ... I might not be able to work or may die so ... yah it may help my daughter".

Meskerem- "I couldn't get any financial support from my own relatives even as a loan to start a petty trade like backing Enjera or bread. I think our society likes to give for beggars who wear dirty and looking sick than for those who need extra hands for sometimes to survive and be able independent like me. Of course, I went to some church based organizations and asked some individuals based on the information I got from others, ... ha ... to your surprise, I got nothing so, I decided not to ask anyone except God who can understand all my problem".

e) Lack of Schools or Training Centers for their Children

These theme discusses about the problems that single mothers of children with ID participated in this study experienced in relation to education and trainings for their children. These days, compared to the past three or more decades, children with disability are getting better chance to attend the regular schools which are inclusive even though many people questioned its effectiveness in addressing the unique need of each child with different nature and severity of

disability. Participants in this study highly challenged to find schools or training centers while their children have been ready (at least physically) to go to school. As all mothers mentioned that they were waiting that moment for two main reasons. One, as a mother it was their dream to see their children going to school and the other one is it was the only chance for those single mothers to go out for work with no worry about their children left at home alone. However, this was not easy to find the school for their children in many ways. The following are their words about this theme.

Asnakech- *“I found a kindergarten near to my home so asked them to accept my child when she was 5 years. It was too expensive specially for me but I agreed about the payment hoping to work hard all the time. After 3 or ... almost 4 months, they informed me that they couldn’t teach my child. I cried and bagged the director allow my child to stay in the school at least half day and he said, “it’s not a place for your child. she couldn’t learn even a single letter rather she was disturbing others, parents also complained about that. That’s why we decided not to continue with this situation”.*

Meskerem- *Even though I knew that my child has a problem to learn letters and numbers, I preferred to pay school fee just for his staying in a safe place till I came back from my labor work. Unfortunately, many schools where I went to didn’t accept my child. Many of them told me that my child is not “normal” so I should rather keep him at home. Few of them asked me extra payment just for looking after him in the school compound, others also gave me addresses of few special schools in Addis Ababa which were too far from where I was living.*

Birke- *“one of the teacher in one government school refused to accept my child in his class room and said, “if he kills one of the students, who will be asked, I will not take this responsibility I would rather leave the school”. Oh God! ... it was terrible. Raising a child with disability specially for one like me is not as simple as we are talking now. It is full of stress, discrimination, and being disadvantaged at everything and everywhere. It is hard even to imagine my life this way if I couldn’t find the center 12 years before”.*

f) Uncertainty about the Future

Uncertainty about the future is the theme that all single mothers of children with ID in this study are highly concerned to and worried about. According to these mothers, thinking about future make them stressed. They worry about their children's future life in the absence of responsible body considered the nature of disability that their children are living with. All mothers mentioned that they are critically worrying by thinking about what would happen when their children will end up their staying in the center soon and thinking of the "What would happen if I die?". Moreover, what mothers are hearing about others with no disability aggravate their stress by imagining it would be more worse to their children with ID. Information about Sexual abuse, disease, pregnancy, kidnapping and killing are some of additional stressors that makes mothers afraid of their future life with their children. The following are their words;

Meskerem- *"I don't know how I express my feeling about the future. But I think I could say that specially for those like me and my child, ... I think ... it is going to be more challenging than ever. When I realize that I'm going to be weak for work and to tack care of my child as before and when I start to think of my death which is natural, I cry! I visualize my child would be ... alone! ... with dirty clothes! ... with no food ... may be sick and no one noticed that ... oh God! For me it's scary like night mare!"*

Asnakech- *I'm really feel hopeless and depressed again when thinking of the future. When I was informed that my child is going to leave the center next year, I couldn't forget how I feel almost dead. It is only me who understand how me and my child benefited from the center. I could work, get psychological support, have got good friends, my child also being able to play with others, able to speak, wash dishes and simple clothes, keep herself clean. Above all, she was so happy and safe in her staying for more than ten years in the center. Now, she is the one who leave the center as she is 19. Thinking of this by itself makes me worry about the future. What am I going to do?... where will I hide her when I go to work? ... or will I stop working to look after her not to exposed to some evil people? ... if so what do we eat? where do we live with no money for rent ... Truly speaking, I'm in fear of the future".*

Birke- *Right now, I need somebody or an organization who will really help me in my heavy load that is my children's futurity. I don't think that I will be able to carry on this longer. I really*

don't. I have been struggling with my sickness, feelings, emotional and psychological problems for the last 19 years since my husband died. But now, thinking of futurity in relation to my health condition ... yah... it's going to be so hard even for his younger brother to handle the situation in addition to manage his higher education. I wish I could be strong enough till he finishes his study and start his own life. But ... I don't know ... am worrying more about the old one. I'm not sure That I will be able to keep his body and clothes clean twice a day as before because he is now almost in his 20 he became so strong and aggressive beside he will leave the center soon and stay where?... Here the whole day?... if so, I must be with him at home and no income at all. If I allow him out, he may hurt someone if feels upset or the evil people may use him to ... you know? I'm afraid of so many things about the future! I even don't know how am I going to work for our daily bread, to have money for house rent ... I think I should give all my worries to the Almighty God!!! ... otherwise, I 'm going to be crazy!

4.3.3 The Effects of Challenges

This theme explains on the effects of the major care giving challenges of life of single mothers of children with ID. The participants mentioned that all challenges that they faced in relation to caring of their children were interrelated that one causes the other. The effect of these challenges also reflected on different aspects of life of these mothers. Psychological, emotional, social, spiritual and financial problems are mentioned by the participants as effects of challenges that they faced in their life. The following are the mothers responds;

a) Psychological Strains

Meskerem; *“you know...? In my case, people's reaction (including my family), towards me and my child hardly affected my life in different ways. I have been so sociable and confident enough to do whatever I want to do, but now ... my social life is too restricted because of their approaches expressed by actions and words made me uncomfortable so I preferred to stay away from them. I also realized that I have changed in my behavior, ... and ... I sometimes become rude and even insult people on the street when they stare at me or my child, ... you know ... I can't control my emotion.*

Asnakech -*“Because it was my responsibility and I had no one help me since my husband’s death, I have been working hard in carrying bricks and stones in some construction sites, so I became severely sick and I’m still with sever heart and kidney problem. Moreover, thinking of my daughter’s future life ...make me so stressed and unstable”.*

Birke- *“I have faced so many problems starting from the begging, mistreated in health care center, discriminated by local community, isolated from the family, lack of psychological and any means of support from anywhere and that made me so weak and hopeless till I found a place for my child, the center. That’s why I wished to die many times in which I feel regret now”.*

b) Emotional Disturbance

Asnakech *“Those challenges in which I passed through didn’t end up by themselves rather they created other problems in my life. They were like a chain ... when I struggle to work hard to cover all the expenses, I failed to manage my health problem and when I tried to take care of myself I could use the money which I safe for my child in case of my ... my absence ... so, ... then, ... when I couldn’t find a job or feeling sick or tired, easily felt upset and, ... started to be complaining to God about everything, I sometimes even I don’t want to pray, ... yah ...that’s what I feel sometimes, ... like it’s useless, ... then, again feel regret.*

Birke *“... now I understand that I’m not cursed or doing something bad more than anyone in the world to have a child with a disability, but what makes me feel bad is looking people’s action wherever they see me and my child. I couldn’t tell them that it is hurting me a lot, ... I wish I could tell them not to show me their sympathy with their action or facial expression rather it would be better to leave us alone if they couldn’t do somethings good like understand how I feel bad when they stare at me or my child”.*

c) Health Related Problems

Meskerem *“... but I have been hardly affected by many problems happened in my life so that I ... think I have changed in my behavior ... I mean I become ... aggressive, or easily annoyed and ... feel hopeless. Moreover, I blame my husband that he betrayed me and my child, I also blame my mother and other relatives for their misunderstanding and mistreating me and my child, ... I*

don't know ... but in anyways, I didn't want to be close to or discuss with them about my problems ... I just didn't. I think this in turn might hurt me more. I'm still between my mother and my son, so to make everything smooth, I may smile while I want to cry, and ... I'm living just for my son ... to whom shall I give him ...always feeling worry about him, ... and as a doctor told me that is why I became diabetic with high blood pressure that hinder me not to eat whatever I get and work hardly as before”.

Belaynesh “... I know that my older daughter will be always dependent on me and God, but I'm also worry about the younger one. I need her to be strong enough to lead a better life, she should be stand for herself but, I'm also become weak and with no helper even in my thought. ... I'm afraid that people may attack them if they know that I'm a single mother and no one is looking after them ... I mean a man ...you know? ... I sometimes feel that we are exposed for any problems at any time, ...so, ...I pray that if it will be the will of God, it would be great if I die with my older daughter.... I don't want to see my younger daughter will be responsible for me and her sister. I don't want her to suffer in her life... I wish her a better life ... so we shouldn't be her burden, ... no! ... I will not allow this happen. I don't know what God will decide for us ... I let him to do his will in our life”.

d) Social Isolation

All participant mothers explained that they had experiences isolating themselves from any social gathering due to people's reaction towards their single status and their children's disability. As they mentioned that the existed traditional attitude of the community disregards mothers when they have children with disability coupled with partner's death or divorce. This resulted the mothers hide themselves and restrain from any social gathering and involvement. Mothers stated this;

Meskerem- “... I isolated myself from many social events, even in my family, because they didn't draw attention to my problem, rather they blamed me for what happened in my life. They considered that I'm misfortune or unlucky one.”

Belaynesh- “...what matters my life right now is forced my child to keep him in door while he wants to stay outside playing with other children. Sometimes, I allow him stay longer to play

with other children, although some parents came and ask me why I let him or send him out that they fear he might hurt their children so I prefer to stay in our small house specially in the weekend”.

e) Financial Crisis

Financial limitation is one of the persistent challenges of mothers’ as the result of dropping their daily business frequently due to their own health problems in addition to spending much time for caring their children. A mother explained this;

“oh, ... of course it is going to be even worse, ... I’m not sure that I will be able to work the whole day as before and get enough money for our food and other expenses. Now, I become feel tired and afraid of the future, ... if I couldn’t get the money to buy food, which is so difficult to explain the reason to my daughter why I there is no food for a single day, and I’m afraid that she might be a beggar on the street”.

f) Spiritual Crises

Spiritual problem is the other dimension of effects of major challenges in mothers’ life. They also explained that sometimes, when all the problems surrounded them, like when they feel sick or no job or money for food ... they couldn’t resist all these problems, they complained of God and refuse to pray or do their spiritual practices what they used it before. A mother added that,

Meskerem *“I usually decline to worship and give thanks for my Lord when I felt that God did not hear and see my ups and downs with my poor child.”*

“... yes! I remember that some of them told me that they thought that they were ‘un known’ even by God since they came here and mate other parents and teachers”. (Assistant coordinator)

4.3.4 Coping Strategies

Most of the mothers’ responses on the strategies that they used to cope up the challenges focused on their spiritual believes, like praying, fasting and attending church ceremonies. They also

mentioned that the relationship with other families of children with ID in the center and having good relations with teachers make them to see life in a better way. Moreover, hoping to see bright future about their children's life helped them to keep struggling their current life and not to give up easily.

a) Spiritual Believes

Asnakech *"As I believe that I would pass all those challenges, with the help of God, ... I used to fast and praying. I was asking God to give me strength to work and a safe place where I should leave my child during my working ours, and ... he gave me that, so I'm still count on him for the future. He is the only means for me to see the future too"*.

Belaynesh *"because I mate few thoughtful people and their words, ... moral support, ... was like a light in my darkness and power to my weak ability in dealing with my child's problem. It also helped me a lot in doing my best to be strong enough. Moreover, the psychological support and advice I have got from the teachers and administrators in the center regenerated my interest to live for the sack of my child. On top of that, my relationship with other mothers having children with ID enabled me to change my perception about myself and to have endurance in my life"*

Birke *"... yes, when I realized that my child was not normal, I decided not to go back to my home land, ... because I was afraid of my family's action to my child that was highly dominated by traditional believes and practices. Not only that, in my community, it was not acceptable for a woman having a child before marriage. Being a single mother in case of separation or death of husband also had its own negative consequences in the entire life of the mother, so ... though I had families there I preferred to stay here with lots of sufferings. ... it was my word to myself not to be beggar till the end of my life, instead work hard day and night as much as I can. Cleaning, washing clothes and backing Enjera were some of my gobs caring my child in my back. I convinced myself that I was responsible to my child and accepted him as a gift of God so, I think, ... yes, ... I did all I could do which is expected from me and for the rest of my child's life, I hope that God will do something better! Yah, it's really my hope, nothing else to reach today, ... I think that was the reason to see my child in this condition"*.

b) Hope

Hope is used as one of coping strategies that mothers explained they could get energy to continue their struggling and it helped them not to give up. As all mothers mentioned that their life is full of very little ups and too many downs, it would have been too hard to reach here if they didn't hope better days for their children, for their health, financial as well as social problems. They said;

Asnakech *"I think hope is something that God gave me next to my child. No matter it would take longer time or challenging, it was my hope to see my child would be able to walk, to speak, ... and I got energy to do my best for that. Whenever I could see the small step and very slow progress on walking or other skills, ..., it might not visible for others, but I, ... I refilled to have a hope to see my child could be running, playing, toileting, dressing, ... oh yes, it would be so hard specially for me to reach here and see my daughter without having a hope ... I might not be alive so as my daughter, ... yes I think like that"*. This result is also supported by other study findings that hope was used as a coping strategy by mothers of children with intellectual disability (Mabel, 2017; Kearney & Griffin, 2001; Heiman, 2002; Kausar & Sobsey, 2003).

c) Developing Relationships

Relationships with other parents of children with disability is one of the coping strategies used by mothers. This relationship was established since their children joined the center. During the interviews, all participants acknowledged the coordinators and mainly teachers for their effort to convince them to attend some trainings given to parents and they paved the way and facilitated situations to parents to uncover their issues to each other. In the beginning, these mothers were impressed by others' freedom of sharing to and gaining from others' experiences. According to their explanation, after two meetings, they became no longer listener rather they also shared their own life experience.

They mentioned that other mothers of all children in the center were like mentors on how they trained their children to use the public transportation together with other children, how they supported them in developing simple routine tasks at home and enable the children to be less dependent in daily livings kills...etc. Moreover, as they mentioned, almost all teachers' approach

to children and parents make them feel belonging to the school community not stranger. The result from FGD with senior teachers also support the idea mentioned by mothers. Making mothers feel free to gain and share their life experiences with each other is one of the oldest culture of the center. Teachers also explained that most mothers were so depressed and lonely when they came to the center for the first time. They needed more human elements like friendship, discussion and socializing than other means of supports. And that's why the center facilitated the situation for parents mostly mother to get together for discussion and have tea and coffee. This bridge the gap between their need and the support system that many mothers missed throughout their life. One mother stated,

Meskerem *"whenever I attended the meeting or training for parents, ... I feel like I am in my family, it is helping me a lot to realize that I am not the only one who is challenging and gave me power to go further to support and share my experiences for others, ... I mean for new mothers"*.

Asnakech *"... for me, ...it's a big chance to have people concerned to others, like teachers in the center, and have friends to share my feelings, and above all, I feel so relaxed when I see my child plays freely with his friends"*.

Birke *"... since I came here, I feel like I have families thinking of me and my child. Teachers, children, admins and other parents are like my brothers and sisters. Above all, when I see my child, ... always feels happy to come and stay the whole day here, in a clean and secured compound and having friends, getting different trainings. ... I wish I could do whatever I can to make this long lasting to see my child always happy with his friends in playing and doing something essential for the rest of his life ... may be ... in the absence of me"*.

4.3.5 Mothers' Wishes and Aspirations

These theme is consisting of ideas, wishes and comments of single mothers of children in relation to what should be done to make future life of mothers and children with disability more better. Although different support systems and strategies can be designed and implemented to solve the problem facing both mothers and children with ID, how much are they effective in addressing the exact need of the beneficiaries is still a big question. Participants in this study mentioned their point of views in relation to what would be best to make their future life better

than before in caring their children and to be stronger and live longer. The followings are their responses;

Asnakech “... I wonder why many people think that I’m always in need of food or ... cloth or something like that. ... you know ... I might need those things but not always as I need someone who wants to be close to and accept me and my child as good friends or neighbors. Sometimes you might sit in one corner of the street, ... in my case, one day, when I brought my child from the center, I felt tired (I’m diabetic), so I sat down next to bus station with my child, ... then, people started throwing cents to me instead of asking what happened or what I need at that specific moment. I tried to show them that I am not a beggar and need some rest and water, but no one could pay attention ... and I would say ... people should be aware that a person like me doesn’t necessarily needs money to live than being accepted or understood by others

. “...because I got the perfect place to my child, I could work freely the whole day and get income. Moreover, I feel secured that my child spends the day in a safe place getting love and freedom to play in addition to education and training. This worth more than a billion Birr for me ... it is my wish for other mothers to get this chance as well”.

Meskerem- “considering my own life, having better diagnosis and referral system would be more urgent need for mothers of children with disability. ...I can’t forget how I have been suffering with this. It was a long process and expensive to get service for diagnosis in which I almost payed everything I had. So, I would say that it would be so good if the health care services could be accessible and considering the life of single mothers with un healthy child... and ... it would be great if some professionals be afraid of God in treating poor mothers and children with mental problems like me and my child”.

Belaynesh...but I think, ... young children should start learning about other children with disability in the school to have a better understanding will and help our children in the future, ... and I think, ... for me, ... young children are closer than adults to understand me and my child though they forced by their parents not to play with my child, ... oh!!! Moreover, ... if it would be possible, ... a place, ... I mean, schools, ... or centers! like CMCC would be expanded for children with ID as they have nowhere to go for schooling, ... I don’t know, ... I couldn’t see a

place like that for my child, ... and it is also my wish to find whatever the job is that my child engaged in even with no or very low payment.

Birke- "... Yes, if you ask me what I'm thinking, ... I better say what I dream, ... the working area, which is safe for me as I'm single and unhealthy and for my son that he will be no longer a child, ... so, if I would see my son engaged in whatever simple work till I am in life and if somebody, ... I mean, ... like an investor to build a very big center and take the responsibility of children like mine after the death of mothers or after he left the center, that would be more blessing for me. ... that is a ... place where I wish my child would live forever, ... to be secured or protected from ... I mean he can't protect himself from ... you know what's going on these days ... it's very difficult even for those who are 'normal' ... living peacefully with no sexual or other forms of abuse".

CHAPTER FIVE

DISCUSSION

In this chapter, findings identified in this study will be presented compared to results from different researches. As previously mentioned in chapter four, five themes were explicated through the process of analysis. So, generally based on the following major themes of this research and particularly in analysis, I have presented the discussion section as follows; major themes- a) Journey to unexpected reality, b) Major caregiving challenges, c) Consequences of care giving challenges, d) Coping strategies and, e) Future perspectives/ perceived needs of single mothers.

Journey to the unexpected reality

For a single mother, having little or no knowledge about disability, the time before and after diagnosis to understand what happened to her child is extremely difficult. It would be even worse if the mother is living in a society in which cultural and traditional practices are considered as effective means to solve children's health related problems than medical treatment (Lauren, 2015; Dibakone, 2016). This is also evident in this study that mothers have been overwhelmed in searching of their children's problem, understanding the problem and finding the solution as well. In this process, mothers explained that they passed through different situations and practices including traditional practices, following individual advice/ information and medical diagnosis.

As many mothers living in Africa, particularly in Ethiopia, all participants in this study mentioned that they exercised different traditional practices to find the best solution for their children's "abnormality". Though these mothers are single and didn't get the psychological or financial support from their families or relatives, they were going wherever they think they could find the solution and in most cases, they did whatever they ordered to do by well-known 'traditional hillers'. According to their explanation about the result of their effort going through this avenue was wastage of time and money with no change in their children's situation.

The other way that the mothers in this study used to know the existed situation of their children was following the individuals' information and advices. It is not surprising if one could hear when mothers explained this situation as "confusion and ambiguous". Because some of the information were about the use of medical treatment and led them to hospitals for diagnosis while others told them that of their children's problem as never addressed by medical treatment rather by traditional ways, which some mothers already gave up with. As it was evident in the study findings, all mothers were confused and almost all were dealing with both at the same time. And mothers believed and said, their low level of education and absent of partners in sharing responsibility or making decisions about their children's life were main reasons for unspeakable confusion they were in before they tried the last one.

It's also surprising that even though these mothers are single, discriminated or poor, they never gave up in looking forward not only the cause also the best solution for their children's problem. The last means that mothers used to know the reality about their children's situation was going to hospitals for diagnosis and did their best in following the information and schedules for like checkups, therapies and other services. However, all mothers, except one, mentioned that they couldn't even understand properly what diagnosis mean and what the doctors told them about the diagnosis result. This result also supported by previous researches (O' Halloran et al. 2013) Mothers also mentioned that they were asking other educated people for clarification what was stated in the medical certificate about the result of diagnosis. As one of the mothers stated that was an evident from the interviews that because they couldn't get clear explanation that considered the mothers' level of understanding about the medical words that Doctors' were using and lack of effective communication skills of some health care professionals.

As many research findings revealed that Caring for children with disability is exhaustive for parents specifically for mothers as they are a sole provider for their children. It's also common even in some developed countries raising a child for a single mother who lost her husband/partner in the case of death or separation. One can easily understand how difficult for this mother if the child would be with a disability and if a mother is living in a country like Ethiopia where being a single mother and having a child with disability has negative implication on the life of mother and her child. This is the reality that the mothers in this study mentioned as number one care giving challenge. Unlike some previous research findings, the finding in this study clearly

indicated that separation/death of husband or partner is mentioned by mothers as problem not by considering lack of financial support rather lack psychological support and societal reactions towards single motherhood.

The other care giving challenge thoroughly discussed in this study and mentioned by mothers is family/societal reactions towards their children with ID disability. Mothers also explained that it is hard to tolerate the day to day dramatic reactions of people on the street or when the family members treated their children as if they are 'non-human' or 'useless'. These social stigma and discrimination also generated stress and emotional disturbance which in turn mothers sometimes misbehave and angry at people. This result also supported by some other study findings in different countries by different researchers, (Intellectual Disability Rights Services, 2009; Kearney & Griffin's, 2001; Mathilde et. al, 2006)

Moreover, fear of traditional believes and existed harmful practices towards children with disability by the community hinder most of the mothers to go back and live in their home land. Isolation and social stigma over dosage traditional medicines for both mothers and children might be some of action

Poor diagnosis and referral system also mentioned by mothers as major care giving challenges in this study. Although these mothers went to health care centers lately due to several reasons as mentioned before, the long process for diagnosis with no clear information about what was going on and poor referral and guidance system, in addition to un expected expenses were challenges that mother were faced there. Many studies also have found related results in this regard, (Esdaile and Greenwood, 2003; Ergu'n and Ertem, 2012;) .

Moreover, these mothers explained that they were poorly approached by some health care professionals while asked for clarification related to the diagnosis process as well as the referral system. This result is supported by also other related research results as presented in the literature review (Melford, 2015; Cerqueira et al.2016)

Lack of education and training for their children also big problem that the participant mothers in this study faced while their children reached at school age and even above. As these mothers explained that they have visited many schools found in their living areas. However, none of them

have been ready to accept their children because of so many reasons like, these and similar responses from teachers and school administrators highly affect the mothers' QOL that refers to the overall wellbeing of mothers.

For a single mother, leading life in the big city with no permanent income or monthly salary in addition to raising a child with ID is extremely difficult. Findings in this research uncovered the reality that these mothers have been challenged by lack of financial support and employment opportunity or very low wage. As mothers explained at the time of interview, they had some unforgettable days and nights with no food because they couldn't have enough for their children and themselves and no one could help them at that time. Some of them also mentioned that some days were even worse when they have been sick, and unable to go out for job. Others also memorized that there were days, weeks and months not to find any job while people couldn't notice that they were nearly to die with full of stress about their children medication, food, house rent, ...etc.

The other major challenge that these mothers were being challenged and still seeking of the solution is the uncertainty about their children's future life. This issue was mentioned repetitively by all mothers as well as by others participated in this study. This implies that how the problem influencing not only the life of single mothers of children with ID but also others' who are concerned and thought full people. The future life of children with ID is the most crucial issue that mothers extremely worrying about because of the nature of the disability that their children are living with. What one could understand from each mother's response related this issue is that they were and are doing their best for the better and secured future life for their children paying as expense as health, happiness and almost their entire life. On the contrary, the problem is becoming more severe and complicated when children become older and mothers also weak and unhealthy. Moreover, this time, when children are nearly end up their staying in the center lasting from 8-10 years, the situation seems invisible and insignificant for others while is creating stress, anxiety and complicated health problems in mothers' life. Teachers and admin staff in the center also shared this hidden reality that mothers are dying with and they mentioned that even if they did what they could in helping children to develop some self- help skills trough years, they still need others' protection and caring specially in the absence of mothers.

Effects or consequences of challenges

The result of the present study on the effect of challenges in mothers' life get some supports from previous research findings mentioned in literature review. As mothers stressed on and explained in detail about the negative effects of care giving challenges manifested in different aspects of life. These are mainly psychological strain, emotional disturbance, social isolation, financial limitation and spiritual disaster. Although the level of challenges of single mothers of children with disability differ from individuals to individuals' due to different factors like nature and severity of the disability, the effects of the challenges in this study highly supported by other research finding conducted by different researchers (R Hassall et al. 2005; O'Connell et al.2013; This indicated that weather mothers are facing different or similar caregiving challenges in relation to raising their children with disabilities, mostly because of the unmet perceived needs, the consequences are more or less similar.

Mothers also explained that although they have changed in their attitude about having a child with disability is not being cursed or other causes related traditional beliefs, they still being hurt psychologically by the influence of others' reactions for them and their children. They also mentioned that they usually upset with and unable to accept or tolerate the kind of actions and expressions of others' including their own family members. What the researcher could understand from mothers' explanation, though they accepted and doing their best dealing with their children's lifelong situation, the unchanged people's approach for both their children and themselves make them too aggressive.

Social isolation also mentioned by mothers that emerged as one of the effects of major challenges they faced in their life of raising their children with intellectual disability. This result also supported by other study (Mabel, 2017; O'Connell, et al., 2013; S'lungile, et al. 2015). During interviews, mothers explained that though they need to be part of the family, neighbors, and the community, fear of others' feedback make them isolate themselves and preferred to stay in distance. They experienced discrimination and stigma directly or indirectly by people around them including families because of their singleness and being a mother of a child with disability forced them to lock their door after them with their children.

Financial limitation is mentioned as another effect of major challenges by the single mothers in this study. As they explained, because they became weak and unhealthy to work hard as before and have no one to just share their burden, they get a financial problem to cover daily expenses and monthly pay for house rent.

During FGD, teachers also strongly support the mothers' response that since these mothers are living almost half of their life working as daily laborer, carrying their children and all the burdens, currently they become weak and with some chronic health problem so they have no power remain to work hard as before. Moreover, the children's need become increasing so these mothers are in need of support not only financially but employment opportunity considering their current situation and their children's future life.

The other main issue mothers raised as effect of challenges is spiritual disaster. All mothers mentioned that there were times that they even totally stop praying though they know that God loves them and their children. Because of all the mentioned major challenges, mainly having no one like a friend, a neighbor or a family member to be closer and share happiness and sadness with them created the sense of 'un wanted' and they thought that 'God is not fair'. As a result, as all mentioned clearly, they stopped praying or attending programs or reading the word of God for about 1-2 years. Some also mentioned that these times were those they extremely being lonely and wished to die together with their children.

Coping strategies

This study revealed that although all single mothers passed through unpredictable and uncontrollable life, more downs and little ups, in raising their children with ID, they also used different mechanisms to survive and passed through the situation which were seemed never pass. All participant mothers also mentioned that they are believed in God and engaged in praying and attending church and read word of God to get strength, health and any means of daily bread for their children and themselves. Some of them also mentioned that though they sometimes might get angry at people or their own children's behavior and then complaining God for everything, they also regret for their thought and started praying in which they feel refreshed and get strength to pass through even the most difficult situations in their life. Others also explained that they feel

not alone but so closer to God to show him their life which is not seen by their families or neighbors or others.

N.B Here the researcher wants to make clear that the issue of spirituality mentioned by mothers in two different situations. In one way as effects/ consequences of challenges and on the other way as coping strategies. However, during the interview session, mothers clearly explained that it is true that they faced spiritual crises when they were in undefined complicated situations especially before they understand and accept their children's disability. Mothers also mentioned that they believe in God although situations forced them to complain on him, "his merci" make them strong to carry burdens and survive with taking care of their children.

Developing relationships with other parents of children with disability is one of the coping strategies used by mothers. This relationship was established since their children joined the center. During the interviews, all participants acknowledged the coordinators and mainly teachers for their effort to convince them to attend some trainings given to parents and they paved the way and facilitated situations to parents to uncover their issues to each other. In the beginning, these mothers were impressed by others' freedom of sharing to and gaining from others' experiences. According to their explanation, after two meetings, they became no longer listener rather they also shared their own life experience. They mentioned that other mothers of all children in the center were like mentors on how they trained their children to use the public transportation together with other children, how they supported them in developing simple routine tasks at home and enable the children to be less dependent in daily livings kills...etc. Moreover, as they mentioned, almost all teachers' approach to children and parents make them feel belonging to the school community not stranger. The FGD with senior teachers also support the idea mentioned by mothers. Making mothers feel free to gain and share their life experiences with each other is one of the oldest culture of the center. Teachers also explained that most mothers were so depressed and lonely when they came to the center for the first time. They needed more human elements like friendship, discussion and socializing than other means of supports. And that's why the center facilitated the situation for parents mostly mother to get together for discussion and have tea and coffee. This bridge the gap between their need and the support system that many mothers missed throughout their life.

Future perspectives/ perceived need

Lastly, mothers were expressed their ideas on what should be done in the future. Surprisingly, the result indicated that all mothers' responses in this regard contained not only their present perceived need but considering the need of new mothers' in the future. Access to diagnosis, referral and other health care related services, teaching new generation about disability, developing education and training system for single mothers and their children with ID and creating integrated job opportunity for children with ID are the mothers' responses on what they think would be done in the future. As it's mentioned earlier, these mothers are becoming feel tired and un healthy due to different factors they always feel afraid of the future to their children in the absence of them. During interviews, each of them raised their ideas on what they think would be good not only for them and their children but for the new mothers having a child with disability too.

Because these mothers faced number of challenges in the process of diagnosis and other services including lack of clear information from health care providers about their children's real situation, they mentioned that they do not want to see other mothers facing the same problem. mothers of children would be treated equally and should be continued and they wished to have better hospitality in healthcare centers for mothers and information should be clear and on time.

The other dimension of mothers' future perspective focused on teaching young children about disability and people with disability. Surprisingly, these mothers highly believed that instead of "*struggling*" with adults, to change their persistent and culture dominated attitude, they mentioned that it would be easier to teach the new generation and possible short cut to make a difference. Mothers also mentioned that most of the time, young children, their neighbors, or others who passed by the road with their parents, want to be closer to and play with their children though their parents do not like it.

The issue of accessibility and affordability of schools or training centers for children with ID also mothers' perspective in which they think future mothers of children with ID and their own children as well as themselves will be more benefited. All mothers remembered how they suffered in looking for school for their children when they were around five or six years old. During the interviews mothers explained that some schools were too far from their house, others

were too expensive which mothers couldn't afford, some of them were also nearby but they didn't accept their children because of their disability. Having this passed experiences, mothers mentioned that find schools like the center (CMCC), have more than one meaning in the life of single mothers of children with ID. As all mentioned during interviews, the center is not only serving as school for their children, they recognized the overall services that they are still getting from as mothers. Workshops on how they manage children's situation including their behavior at home, trainings on how to start small businesses with small startup capital on loan bases, counseling and psychological supports are some of the services these mothers have got from the center.

Documents or folders also used as extra sources of information about the progress that each child exhibited since he/she started training in the center. Students have two folders in the classroom. One folder contains all detailed information about the student's history like copy of birth certificate, diagnosis result, medication he/she used or still using, individual educational plans and progress reports ...etc. the other folder also contains all the student's classroom activities, like writing and drawing, cutting and gluing, painting, sewing and all practical activities from fine motor and coordination skill development practices and other related trainings. The sample of each practical activities in the second folder (document) for each child in the classroom, full of samples of practical activities are more evident for mothers' explanation on how their children showed undeniable progress in their understanding, coordination, self-help skills and the like. Each piece of work found in the folder with name date, month and year which clearly indicated how far the particular child is in progress since joined the center.

Creating job opportunity after trainings and establishing social security for children with ID for the rest of their life also the most important and strongly raised from the participant mothers. On their point of view, their children's future life is undefined and they will may be at risk even to survive if their mothers, soul providers die. According to single Mothers participated in this study, currently, more than any kind of support for mothers or their children with ID, they want to hear about or see when people pay attention to what should be done to minimize risks and maximize opportunities to work, socialize, and make children's life more meaningful. As they genuinely explained that the support system would be more effective if considering what mothers are really need. Moreover, they explained about the importance of community

involvement in taking responsibility and initiation to make the support systems integrated to address the social, economic and psychological aspects of mothers and children's life.

Surprisingly, these mothers mentioned their wishes and aspirations on what would be done for the future life of their children and the new mothers having children with disability rather than focusing only on their personal and current need. They frequently raised and explained the importance of vocational trainings for their children and creating job opportunity considering the children's limitation. Moreover, mothers wish to see where their children will be and how they lead the rest of their life in case of their absence. However, currently, there is no existed and defined social system that specifically considered the nature of intellectual disability, no social security for these specific group of individuals except few centers involvement in giving some vocational trainings for children with ID in Addis Ababa.

Limitation of the Study

One of the limitation of this study was the limited evidences on the diagnosis result of children with ID. Although all 4 children have legal medical certificates from government hospital with their name and dates, the result indicated simply that the child is "Mentally retarded". There is no other explanation about the assessment tools, level of severity or related details. The other limitation that the researcher found unmeet plan to get additional information from other individuals working on disability in other organizations due to very tight schedule to meet them during working hours and arrange time for interview. The researcher also acknowledge that the limited number of literatures directly related to the research topic because of consisting two specific issues, (single mothers and children with ID). Many of these study findings are focused one either single mothers of children with disability in general or mothers' (not necessarily single ones) of children with ID.

CHAPTER SIX

SUMMARY, CONCLUSION AND RECOMMENDATION

6.1. Summary

This study explored lived experiences of single mothers of children with intellectual disability in the “Center for Mentally Challenged Children”, CMCC. The study was qualitative in nature and semi structured interviews were employed with four single mothers of children with intellectual disability. Results indicated that single mothers of children with ID are those who passed through the most dual faced challenges as a single mother and as a mother of a child with disability. The findings showed that traditional practices, medical diagnosis and information from individuals have been served as paths that mothers passed on to know their children’s situation. Results also revealed the major challenges of mothers in relation to caring their children. Death or separation of partners, societal reactions towards their single status as well as their children’s disability, lack of education, trainings, employment and fear and uncertainty about the future are the major problems in mothers’ life.

Poor psychological, emotional, spiritual, social, and financial status are also indicators of effects of all the challenges that mothers are straggling with makes life more unfair for both mothers and their children. Findings also indicated that spiritual believes, hope and developing relationships with other parents of children with ID are coping strategies that mother used to cope up challenges. Finally, the study results gained from mothers’ perspective on what should be done in the future indicted that the need of access to early diagnosis and referral system, integration of trainings and job opportunities for children with ID, developing education and training system for single mothers and educating new generation about disability are discussed as measures to be taken for better life of mothers as well as their children with ID.

6.2. Conclusion

Single mothers of children with ID are vulnerable for multi faced life challenges because of their single status and due to having a child with disability. However, these existed realities in mothers' life did not get attention by families, neighbors and communities. Little or no attention for the nature, severity, appropriate intervention and training for children with ID as well as failing to understand the need of mothers make the support systems like schools for children and job opportunity for mothers limited and in accessible. The findings in this study showed the major challenges of single mothers of children with ID, the effects of challenges in mothers' life, coping strategies used and future perspectives of mothers (their point of views). The results also indicated that communities attitude towards single motherhood and disability is still culture dominated and unchanged even in Addis Ababa. So that it is influencing the process of early identification, intervention and support system towards the children's disability as well as addressing the social, financial, emotional and psychological needs of these mothers. Teaching young generation about disability, integrated training and education system with employment opportunity accessible and affordable health care services with integrated referral system are also raised as measures to be taken in order to minimize challenges and maximize opportunities for better life of mothers as well as their children with ID.

6.3. Recommendations

Using qualitative data, this study has pointed out the unique and challenging life experiences of single mothers in the case of Center for Mentally Challenged Children (CMCC). However, the findings highlighted the need of further researches for detail information and understanding about the real-life situation of these specific group of people in different sub-cities, cities, regional states as well as nationwide. The researcher also highly recommends the importance of establishing scientific based and reliable assessment and diagnosis services system. Accessible and affordable diagnosis service would be critically important for early identification and intervention. Moreover, it prevents mothers from unnecessary expenses and confusion and also children from sever and complicated problems. Revising or creating the better support system with taking in to consideration the specific needs of mothers and including their point of view while planning support systems and rehabilitation programs would make the result effective.

Moreover, support systems, in addressing the issues in the life of children with ID and their single mothers would more meaningful and consistent if it would be started to implement at family, community and institution level.

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Appendix A

Semi Structured Interview Guide

- Overarching Question; Tell me about how it is like to be a single mother and caring a child with ID?
 - = Probes
1. Tell me about your life before getting birth of (the child's name)?
 - How do you express your relationship with your partner?
 - What was the reason for you to become a single mother?
 - How about your relationship with family and friends?
 - Did you have a job? What did you do? (If not, why not?)
 2. How was the situation at the time of getting birth of your child?
 - Where was it?
 - What was your feeling when you see your baby for the first time?
 3. Tell me about your experience of finding out that your child had intellectual disability?
 - When did you know it?
 - How did you know it?
 - How did you feel?
 - How were you treated by health care professionals or other family members?
 4. Tell me about the situation after you were aware of your child's condition?
 - How prepared were you to care your child at home?
 - What was rewarding?
 - What was challenging?
 5. Tell me about how you manage the challenges and who else has been involved in care for your child?
 - How do you express your families, friends and other relatives support?

- How do you express the support from health care providers and other professionals?
- Were you getting any formal/ informal support from the community?
- How do you make time for yourself?

6. Tell me about your family life. Is there any change because of having a child with intellectual disability?

- What has been a positive change?
- What has been challenging to adjust to?

7. Tell me about the effect of caring your child in your life?

- What has been positive effect?
- What has been negative effect?

8. Tell me about the services that you and your child is getting from the center.

- What are the benefits?
- What are the challenges?

9. Tell me your perspective about you and your child's future life.

- What do you want to see in your child's life?
- What would be your role in your child's future life?
- What would be done by the family, community or government to make the future better for mothers and children with ID?

10. If you could get a chance to speak with someone about your life who would be you want to speak with and what would you want to say?

Appendix B

Demographic Information

Age of a Mother.....

Age of a Child..... sex.....

Child Diagnosis..... When diagnosed.....

Marital Status.....

Employment Situation.....

Level of Education.....

Income Level.....

Appendix C

Addis Ababa University

College of Education and Behavioral Studies

Department of Special Needs Education

LETTER OF INFORMATION FOR PARTICIPANTS

My name is Roman Negash. I am the master's student in Addis Ababa University, College of Education and Behavioral Studies, Department of Special Needs Education. Currently, I am working my thesis on the "lived experiences of single mothers of children with intellectual disability". The aim of the study is to explore the major challenges of single mothers in relation to raising their children, effects of challenges on mothers' life, coping strategies as well as future perspective of mothers on what should be done to minimize challenges. Therefore, it is your cooperation that help the researcher to accomplish the research objectives. So, I am kindly asking you to share your experiences, knowledge and perception.

During our discussion, I want to assure you that the information you will share will be kept confidential and used only for educational purpose. You have also the right to refuse not to answer, and to quit; if you feel discomfort with the questions. All the information that you will voluntarily providing will be coded and kept confidentially. Finally, the findings of the research will be presented and reported to the Department of Special Need Education in AAU. So, if you are willing to participate in the study, please put the sign (✓) on the space provided.

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

Thank you!

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