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INSTITUTE OF AGRICULTURE AND DEVELOPMENT

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Experience of Appraisal, Stress and Adaption of Parents Having Children with Down syndrome: The case of Ethiopian Evangelical Church Mekane Eyesus Center for Mentally Challenged Children

BY

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JUNE 2022

Addis Ababa, Ethiopia

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DECLARATION

I, Azeb Alemu, declare that this work is my original paper which is "Experience of Appraisal, Stress and Adaption of Parents Having Children with Down syndrome: The Case of Mekane-yesus Center for Mentally Challenged Children." and has not been presented for a degree in any other university and that all sources of materials used for the thesis paper have been duly acknowledged.

Azeb Alemu_______________ _________________________ ________________

Researcher Signature Date

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St. Mary`s University

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ACROMYMS

DS	Down syndrome
FGD	Focus Group Discussion
ID	Intellectual Disability
IDI	In-depth Interview
IPA	Interpretive Phenomenological Analysis
LD	Learning Disability
MOH	Minster of Health
NDSS	National Down syndrome Society
P	Participant
WHO	World Health Organization

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ABSTRACT

Down syndrome is a chromosomal condition that occur when an error in the cell division results in a full or partial extra copy of chromosome 21. The additional gene affects the individual's physical features, intellect, and overall development and causes distinctive characteristics associated with an individual with Down syndrome. There are many challenges parents face in raising these special children. It demands a great deal of sacrifice and patience. According to the research finding the main challenges of parents were psychological problems, difficulty to manage the family, economic strains, social stigma and lack of access to facilities and services for their children. The study aimed at exploring the experience appraisal, stress and adaption of parents in raising their children diagnosed with Down syndrome. The study was conducted in the selected organization of Ethiopian Evangelical Church Mekane Yesus Center for Mentally Challenged Children at Addis Ababa. Qualitative method was used and phenomenological research design was employed with purposive sampling techniques to select the participants. Target populations for the study were parents having 16 years old child with down in the organization were selected through purposive sampling technique. The sample size drawn was 25. The study utilized in-depth interviews, FGD, observation and key informant interview as a study instrument. The interviews with the parents were recorded, transcribed and analyzed under Interpretivist paradigm along with the theoretical framework of Bronfenbrenner's ecological system theory. The results of the Interpretive phenomenological Analysis (IPA) thematically categorized as: a) Parent initial reaction to the diagnosis of Down syndrome; having wrong perception for the cause of Down syndrome and non-acceptance of children, b) social challenges; concerned about community reaction, social stigma and discrimination, c) psychological challenge, being worried about the future of children and overall emotion impacts of Down syndrome on parents who have a child with it, d) Economic challenge; financial problem regarding to medication, health care and need fulfillments and e) adaptive coping strategies of parents raising a child with Down syndrome. According to the research finding parents having children with Down syndrome experience financial, social, martial, psychological and other obstacle. It was suggested that all segments of society, social worker and government be involved in providing holistic assistance for children and parents.

CHAPTER 1

INTRODUCTION

The study focuses on the lived experience of parents having a child with Down syndrome. The study is about what families face in raising children with such kind of intellectual disability. To begin with, it is important to look the meaning, status and prevalence rate of Down syndrome from the global to local context, where the study will be carried out. Therefore, this section presents some detail on the background of the study about DS and the situation in the World, Africa and Ethiopia.

1.1 Backgrounds of the study

Down syndrome is one of the best-known chromosomal disorder in humans, it is caused by trisomy of chromosome 21. It has an effect on most body systems, giving rise to a variety of characteristics clinical features. The formal story of Down syndrome began in 1866, when a physician named John Langdon Down published an essay in England in which he described a set of children with common features who were distinct from other children with mental retardation (Leshin, 2020) . For many years the incidence of babies born with Down syndrome was found to between 1 in 600 to 1 in 700, although studies in different countries ranged from 1 in 500 to 1 in 800. During the 1990's in most developed countries, the most quoted rate was around 1 in 1000 (Cunningham C, 2006) Now a day the incidence rate of Down syndrome (DS) is between 1 to 10 per 1000 live births worldwide (WHO, 2020).

Persons with DS are highly susceptible to complications like hearing and vision loss, heart defects, obstructive sleep apnea, hematological disorders, and dementia, increasing their need for highly specialized healthcare services. This is because the extra genes affect their metabolism, growth and possibly activity levels. A family that already has a child with down syndrome or a mother whose age is more than 35 years have higher chance or risk than other families to have a child with DS (Piyush Gupta, 2021) . The average life expectancy of a person with DS is about 60 years (Shaziya Allarakha, 2022). However, many factors influence the life span and quality of life in a person with DS. In developed country like United States the life expectancy has remarkably increased over the years due to application of advance in medical science and technology along with greater awareness about the condition.

Down syndrome (DS), the most common genetic cause of intellectual disability, is generally associated with a distinctive phenotype, and may involve delayed growth, additional health problem, and difficulties in carrying out activities of daily living. (Chapman and Heskett, 2000). Families of children with chronic developmental conditions such as Down syndrome face many challenges such as lower quality of life in relation to health, financial well- being, social support and career opportunities. Parenting a child with a disability can be stressful. Research studies have indicated that parents of children with disabilities experience a greater level of stress than do parents of children without disabilities (Rodriguez and Murphy , 1997). Those stress can be psychological, physical, emotional, economic and social.

To the present, the prevalence of DS in African populations is unknown. Most of the widely circulated reports on the incidence and prevalence of Down syndrome in Nigeria and other countries in sub Saharan Africa are estimates extrapolated from statistics obtained in developed countries such as the United Kingdom, United States of America, Canada or Australia. The studies did not consider the influence of factors such as socio cultural, genetic, racial and environmental characteristics on the prevalence of the condition, thus affecting the reliability of the data (Christianson, 1996). In Ethiopia, an estimated 7 million people live with some kind of disability, which represents about 10% of the total population (Sorsa, 2013). However, the country profile focused much on common disability like the blind, the deaf and physically disabled. Throughout Ethiopia, having an intellectual disability is regarded as a source of shame. In most region of the country, families with disabled children are considered to be punished as consequence of “Evil” or an ancestral sprit. In Ethiopia, special needs children are among the most psychologically, socially, economically, and politically disadvantaged (Weldeab, 2007). To put it another way, having special needs frequently entails discrimination, social isolation, and physical limitations (Letekidan, 2003). A society in which habits and customs reproduce inequalities, in which stigmatizing attitudes are common, exacerbates the difficulties for many families (Lam and Mackenzie, 2002). Misconceptions and unfavorable attitudes towards disabilities and persons with disabilities result in continued stigmatization (Weldeab, 2007) .

However, there is number of documented researches that stated the challenge of family in caring for a child with intellectual disabilities, most of the researches on the issue stems from western societies, particularly the United Kingdom and United State of America (Gobrial, 2018). Therefore, further studies are needed in order to better understand their experience. Limited research has been conducted on the perceptions of raising a child with Down's syndrome within an African perspective, this study provides an initial stance towards exploring the experience of raising a child with DS in this context. This study will focus on exploring the challenges, experience and stress of parents in the process of raising their affected child.

1.2 Statement of the problem

Down syndrome has been an existential dilemma for many individuals around the world since it was first discovered in 1862 by an English physician named John Langdon Down, who helped to distinguish the illness from other mental disabilities. Based on the research done in western Austria having a child with an intellectual disability (ID) on the family reflected a pathological model whereby couples and the family as a whole were assumed to experience inevitable negative impacts (Cunningham C. , 1996). Parents of children with DS are having plenty of problems in their life in physical, psychological and social compared to the parents of normal children. Parents of children with intellectual and developmental disabilities, like DS, are experiencing a variety of negative emotions such as stress, anxiety, and depression, as well as increased fear about their own and their children's futures, which will have a negative impact on their wellbeing due to their inability to cope with this situation. (Mona, M. Barakat, Rehab, E. Mohamed, 2019). The increased emotional, physical and financial demands can have a profound impact on the functioning of the family (Dodd .C, Zebra Risky, Widemer M.A,Eggtt D, 2009) .

There are numerous documented studies in Western society that discuss the difficulties of having a kid with Down syndrome, particularly in the United Kingdom and the United States. Relatively in Africa, small consideration has been given to DS and the challenge of parents in the process of raising their children. According to the study in South Africa DS has been a largely unrecognized problem. This would appear because of a lack of clinical awareness of the problem among medical and nursing staff, difficulties in deriving a clinical diagnosis of DS in African neonates, a suspected high infant mortality of affected persons resulting in a low prevalence of DS (Megan D. Barr, Pragashnie Govender, Gina Rencken, 2016) . It is because of limited awareness of the problem in the community. Generally, people with disability are considered as ugly and they are not welcome in society. Because of the society influence, a family with a child who has disability considers this child as a burden (International, 2010). In most places, a family hides their child for fear of being outcasts in the village. They would not consider them as useful to the community. Even in developed countries despite the extensive knowledge of health condition in children with Down syndrome, the impact of Down syndrome on a family's remain understudied (Pediatrics, 2001).

According to the World Health Organization (WHO) (2011), the prevalence of disability in developing countries such as Ethiopia is 17%, however the exact prevalence of people with ID in the Ethiopian context is unknown. In our country, where alternative childcare systems are not developed, families, mainly mothers are the main sources of support for their children's overall development (Woldegebreal, 2014). In developing nations like Ethiopia, the issues families confront in relation to children's ID are more serious and intricate. People with special needs in developing countries have faced numerous challenges because many of those countries' governments have never committed to providing a variety of services to these large group of citizens (Getnet, 2013). In addition to lack of services for children and families, lack of knowledge resulted in many negative consequences for parents. All those limitations increase the burden of family as well as their emotional stress, significant strain on family relationship, change in family role and activities. However, there is no enough research conducted in this area to understand the experience and challenges of family in having a child with Down syndrome. Yet, there are few researches conducted in our country but they are mainly focused on the challenges encounter by parents who have a child with DS in relating to medical service basically, social and economic challenges of service provider in supporting those affected children as well as families and general assessment on the need of families of children with intellectual disabilities. Hence, luck of sufficient research in the area led to information gap that hindered the promotion of the concept in the country. This research tried to fill this gap by providing additional knowledge about the condition, parent experience and challenges in the process of raising children with DS emphasizing on psychological and social aspect.

1.3 Objective of the study

1.3.1 General objective

The main objective of this study is to investigate experience of Appraisal, Stress and Adaption of Parents Having Children with Down syndrome in the selected Down syndrome center of Addis Ababa

1.3.2 Specific objective

1. To investigate the life experience of parents raising children diagnosed with Down syndrome.
2. To find out the social and psychological challenges of parents of children with down syndrome
3. To find out the Adaption techniques used by parents of children with Down syndrome to deal with their issues.

1.4 Research question

1.4.1 Core research question

What is the Experience of appraisal, stress and Adaption of parents having a child with Down syndrome?

1.4.2 Specific research question

1. What is the lived experience of parents in raising children diagnosed with Down syndrome?
2. What factors are associated with stress in parents of children with Down syndrome?
3. What Adaption strategies do parents of children with Down syndrome employ to deal with their children's psychological and social issues?

1.5 Scope of the study

The study focused mainly on Parents who have a child with Down syndrome in Ethiopian Evangelical Mekane yesus Church center for mentally challenged children. Their lived experience in raising children with the condition will be explore on the study. The study is limited on parents who have a child at the age of 16 and above. It helps the researcher to collect more information about what they face on that journey from different experience. The study does not include family of children below and above the mentioned age.

1.6 Significance of the study

The purpose of this study is to determine the impacts of having a child with down syndrome among families who have teaches their affected child at Mekane-Eyesus Center for Mentally Challenged Children.. This study is essential because down syndrome effects on families are broad and intertwines with other aspects of economy, personal life, social life, psychological …etc.

- To assisting the children with Down syndrome to obtain social support and enable them to access the resources and potential to fulfill their needs.
- To the social worker professionals to involve in addressing the problem of family raising children with down by conducting their roles.
- To connect the affected individuals and families to community social service provider institution, such as social affair office, community development institutions and other government bodies for minimizing parents' burden.
- To create awareness in the community to accept the existence of the children with Down syndrome as part of the community member as well as diminishing the negative label and humiliation toward the family and the children with Down syndrome.
- To guide professionals in preparing a plan to counselling and other intervention programs based on the needs of children and parents.
- To develop appropriate care and support systems and intervention programs to bring about sustainable changes to in to the lives of families and children.
- To determine health problems encountered and associated factors; problems of access to health care, rehabilitation center and health information among Children with Down syndrome.
- To investigate the role of family, care giver, social worker and other social service provider in developing and maintaining the social support networks of the children with DS.

1.7 Operational definition of the term

Down syndrome: is intellectual disability which is caused by an extra copy of chromosome number 21 inside each of the body's cells.

Child**:** For this study a *Child* was defined as a person up to the age of 18 years and below ((ILO, 1999).

Parenting: is the process of promoting and supporting the physical, emotional, social, spiritual and intellectual development of a child from infancy to adulthood.

A d*isability* refers to any restriction or lack of ability to perform an activity in a manner or within the range considered normal for human beings (WHO, 2020).

A 'syndrome': means a group of recognizable characteristics

Trisomy 21: commonly referred to as Down syndrome, is caused by an additional copy of the 21st chromosome that typically results from a nondisjunction event during gametogenesis.

Chromosome: is a thread-like structure made up of DNA which is found in the nucleus of each human cell.

Stress: refers to negative emotional experience accompanied by predictable psychological, cognitive and behavioral changes, which lead to changes in perceiving the stressful situation and ability to deal with (Wang, Michaels & Day , 2011).

Social challenges - refer to difficulties that people encounter while interacting with people in society or engaging in normal social behaviors.

Psychological challenges are difficulties that people face that cause them to experience unpleasant emotional states such as stress from managing a child, disappointment and sacrifice, interpersonal conflict, concern about their child's future, and a sense of loneliness, all of which can affect their daily activities.

Discrimination is the act of making unjustified distinctions between people based on the individual or family situation.

Coping is a way of stress management. It includes task-oriented and ego defense mechanisms, responses of individual to stressful situations, and the factors that enable an individual to regain emotional equilibrium after a stressful experience.

1.8 Limitation of the study

The primary limitation for this study was lack of comprehensive data specifically about Down syndrome in the Ethiopian context. In addition to this the sensitive nature of the subject which the researcher was researching, it might have been difficult for some participants to be open and to honestly share their challenges also had created some challenge for the researcher during data collection. Another study drawback was the difficulty in recruiting more willing mothers who met the criteria of having a well-documented diagnosis for their children. Moreover, this study will focus on parents of children with Down syndrome in Ethiopian Evangelical Mekan eyesus Church Center of Mentally Challenged Children and the findings of the study cannot be generalized for the whole population of the project beneficiaries. Hence, parents of children with Down syndrome in another center will not include.

1.9 Organization of the study

This thesis is organized in to five chapters. Chapter-1 is already presented in the above section; the contents of the following chapters are briefed next. Chapter-2 review the related literature focusing on Down syndrome, Risk factors, sign and symptom, cause and parenting with Down syndrome. Chapter-3 presents the methodology used in this thesis. The chapter includes the research approach as well as describes the data collecting and analysis methods used. Chapter-4 will contain analyses and present the research findings obtained through the thesis methodology. Finally, Chapter-5 ends the thesis with conclusion and a set of suggestions derived from the research findings and the conclusion of this work. At the end of the thesis document, references and appendix are included that contain the interview question and observation check list to collect primary data for this work.

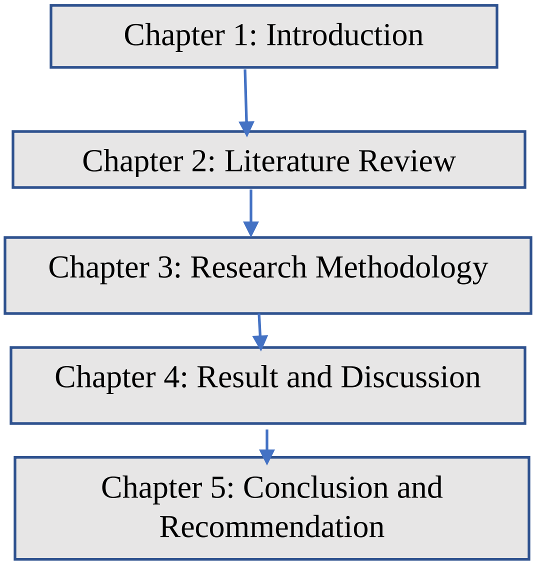

Figure 1 Outline of the thesis

1.10 Ethical Consideration

To collect pertinent data the researcher took support letter from St. Marry University. The researcher was also been obtained permission from the institute to get informed consent of the participants. Participants were aware that participation is completely voluntary and they may choose not to answer any questions for the interview. Thereafter, the purpose of the study was briefly explained to all the participants’ families with the assurance that information given will be treated with confidentiality. Confidentiality of the child with Down syndrome and their family strict adherence to individual privacy was fully assured.

CHAPTER 2

LITERATURE REVIEW

This chapter deals with theoretical and empirical findings regarding the effect of Down syndrome on parents who have a child with it

2.1 Overview of Down syndrome

Down's syndrome (DS) was first described in detail by an English doctor, John Langdon Down, in 1866. It is a congenital condition which randomly affects about 1 in every 700 babies born throughout the world, male and female alike. DS is caused by an extra copy of chromosome number 21 inside each of the body's cells. It is a chromosomal accident, not caused by anything the parents have done before or during the pregnancy, and is only very rarely inherited. Down syndrome (DS) is the most frequently occurring chromosomal abnormality. It results from the presence of an extra partial or complete 21st chromo- some. This increase in genetic material disrupts all aspects of an individual's physical, mental, and social development

In every cell in the human body there is a nucleus, where genetic material is stored in genes. Genes carry the code of the responsible for all of our inherited traits and are grouped along a rod like structure called chromosomes. Typically, the nucleus of each cell contains 23 pair of chromosomes, half of which are inherited from each parent. Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. This additional genetic material alters the course of the development and cause the characteristics associated with Down syndrome. A few of the common physical traits of down syndrome are low muscle tone, small stature, an upward slant to the eyes and a single deep crease across the center of the palm. Down syndrome occurs in about 1 in 700 newborns. About 5,300 babies with Down syndrome is born in the United States each year, and approximately 200,000 people in this country have the condition. Although women of any age can have a child with Down syndrome, the chance of having a child with this condition increases as a woman gets older. Children with Down syndrome experience an array of medical conditions and health care problems which have been widely documented. Although there have been vast improvements in the medical management of these conditions leading to increased rates of infant and child survival, these comorbidities still impact on quality of life for families and children with Down syndrome.

For children with DS, it is widely recognized that the development of movement patterns and the acquisition of motor skill proficiency can be a slow and discouraging process. Although some children can attain a competence level that is somewhat comparable to their peers, motor milestones are generally delayed, and, in certain aspects of motor skill performance, children and adults with DS show a “lack of finesse” often described as “clumsy” ((Henderson, 1986) Jobling 1999a, b; Latish, 2000). For children with DS, discovering the joy of movement can be a frustrating and difficult task. Children born with Down syndrome can usually do the same things as any other child such as walk, talk, potty train, and dress themselves. The only differences between children born with Down syndrome are they accomplish these functional tasks at a later age than other children. Early interventions such as physical therapy, occupational therapy, and speech therapy are best to help a child reach their full potential of development (Edubirdie, 2021). There are three distinctive karyotypes of Down syndrome: **Free Trisomy 21**, **Translocation** and **Mosaicism.**

Free Trisomy 21

This is the most common type of Down syndrome where every cell in the person has an extra chromosome 21; between 90 to 95% of all people with Down syndrome have free trisomy 21. The condition stem from an error in cell division known as “nondisjunction.” At some point leading up to or at conception, in either the sperm or the egg, one of the parents’ pairs of 21st chromosome failed to separate. So instead of getting one chromosome each from the mother and father, the embryo’s DNA ends up with an extra chromosome in the 21st pair as the embryo mature and its cells continue to replicate, the extra copy of that 21st chromosome is replicated over and over in every cell (Heid, 2001)

Translocation

In this type, the extra copy of chromosome 21 is not free, but has attached to one of the other chromosomes – it has **trans**ferred to a new **location**. The most recent studies suggest just over 3% of people with Down syndrome have the translocated type. This type of Down syndrome are physically indistinguishable from those with trisomy 21 but they have 46 chromosome not 47, and one chromosome is larger because it carries the extra 21.

Mosaicism

this type of Down syndrome is when there is a pattern of some trisomic cells and some normal cells. Most recent studies find that just over 1% of people with Down syndrome have the mosaic type, although some earlier studies report up to 5% (Association, 2001). This is the rarest type of Down syndrome, accounting for 1 to 2 percent of cases, and people with this type may have fewer or less-severe symptoms than those with the two more common types of Down syndrome. All these different types of Down syndrome, and any additional chromosomal problems, can be detected by chromosome analysis.

2.2 Risk factors

The extra copy of chromosome 21 can come from the mother or the father. The main risk factor for Down syndrome is a mother age at conception. As a woman gets older, her risk of having a baby born with Down syndrome increases. There are three key factors associated with increased risk of Down syndrome recognized by the (National Down Syndrome socity , 2009). These are:

- Advancing maternal age. A 20-year-old women's odds for having a baby with Down syndrome are 1 in 2000. By the age 35, the risk rises to 1 in 350. At 40 the risk is 1 in 100 and by the age 45, it's 1 in 30. Still most babies with Down syndrome are born to women younger than 35, simply because there are more births in this younger group.
- Previous birth of a child with Down syndrome. Mothers with a child with Down syndrome have about a 1% increased chance of having another.
- Genetic factors. As mentioned above, parents who are carriers of translocation have some increase of incidence of Down syndrome in future conceptions.

Down syndrome affects all people race and economic classes. And though it is a genetic condition, it's generally not passed down by family members. There is a hereditary component with translocation, however, which is one of the more uncommon types of Down syndrome (Lawler, 2021).

2.3 Sign and symptoms

Child with Down syndrome displays the characteristic physical features of the disorder, including epicanthic folds of the eyelids, broad face and flattened nose. People with Down syndrome often have a characteristic facial appearance that includes a flattened appearance to the face, outside corners of the eyes that point upward (up slanting palpebral fissures), small ears, a short neck, and a tongue that tends to stick out of the mouth. Affected individuals may have a variety of birth defects. Many people with Down syndrome have small hands and feet and a single crease across the palms of the hands. Digestive abnormalities, such as a blockage of the intestine, are less common. In addition to these internal and external symptoms, the affected person also shows learning and developmental delays connected with Down syndrome which include speech and developmental delays, attention and concentration issue, difficulty sleeping, delays in cognitive development, mild to moderate cognitive impairments and delayed toilet training (Lawler, 2021).

Complication: children with Down syndrome are at risk for many complications (National Down Syndrome Society, 2009). About half of Down syndrome children are born with a cardiac abnormality of some kind. Children with Down syndrome are more prone than other children to get leukemia. These children are far more likely to get infectious infections, particularly pneumonia, due to anomalies in their immune systems. It's possible that you'll get a blockage in your intestines.

2.4 Cause of Down syndrome

Most cases of Down syndrome result from trisomy 21, which means each cell in the body has three copies of chromosome 21 instead of the usual two copies. Less commonly, Down syndrome occurs when part of chromosome 21 becomes attached (translocated) to another chromosome during the formation of reproductive cells (eggs and sperm) in a parent or very early in fetal development. Chromosome 21 is the smallest chromosome, but it contains about 40 million bits of code (see later, genes and codons). Recent estimates report that chromosome 21 contains 329 genes, around 1% of the total human genome. Not all the genes on chromosome 21 are associated with Down syndrome. Most of the physical characteristics of Down syndrome result from extra copies of the end of the long arm of chromosome 21 (Cunningham C. , 1996). Affected people have two normal copies of chromosome 21 plus extra material from chromosome 21 attached to another chromosome, resulting in three copies of genetic material from chromosome 21. The cause of extra full or partial chromosome is still unknown. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome. However due to higher birth rate in younger women, 80% of children with Down syndrome are born to women under 35 years of age. There is no definite scientific research that indicate that Down syndrome is caused by environmental factors or the parents' activities before or during pregnancy.

2.5 Being the parent of a child with Down syndrome

Parents of children with Down syndrome have to carry heavier responsibilities compare to those of normal children due to the challenges and obstacles they are facing as the consequences of the condition of Down syndrome. The family's behavior and attitude toward the condition of the children with Down syndrome are different, because naturally, every parent would want their children to be born in perfect body and healthy in physical and mental. Anggreni & Valentina, found from their research that most parents gift with children with down syndrome are experiencing feeling of sad, disappointment and shocked when they learned that their children were born with down syndrome, although in the end, the parents are accepting the condition of their children with down syndrome (Anggreni N Valentina D, 185-197). Based on Roos study in 1963, parents who have a child with disability like down syndrome experiencing common pattern of reaction that include (a) loss of self-esteem, (b) shame, (c) ambivalence, (d) depression, (e) self-sacrifice and (f) defensiveness. The intellectual health condition that different from other children make them need more attention and special treatment from their parents. The parents usually experience several problems such as how to communicate the condition of their children to other family members, the expenses and budgeting managerial, treating other family member because the parents often pouring down more attention to the children with disability, treating children with down syndrome itself becoming another issue as well as providing good education thus the children with down syndrome can grow up independently and better in the future (Anggreni N Valentina D, 185-197). Some societies still believe that Down syndrome is a curse for a family, thus the family consider the person with Down syndrome as the embarrassment for the family. As the effect of that believe, many parents are covering the fact that their children are having Down syndrome. Although the overall impact of parenting a child with a disability can be stressful, the impact may be less severe than what is often assumed

(Risdal Singer, 2004) . In reality, problems and stress have been shown to be lower in families of children with DS than families of children with other disabilities.

2.5.1 Social challenges of parents having a child with Down syndrome

Most published studies, conducted in rich industrialized countries, pay little attention to the characteristics of the society. Despite this dearth of evidence, it is likely that not only access to services but also social norms and values influence what adapting to parenting a child with an intellectual disability entails (MS O'Shea JM Giro´n Cabrera , 2012). A society in which habits and customs reproduce inequalities, in which stigmatizing attitudes are common, exacerbates the difficulties for many families. In African context for many years, the child with ID like Down syndrome has been a source of disappointment, unhappiness, and regret because of the societal belief system, attitudinal disposition, and lack of service for these individuals and their family members. There is ignorance which leading to human rights abuses, discriminations, lack of social acceptance, and general negative attitude to the child and the family (Owoade Philip Adeleke, James Abua Ewa, James Eburikuri Olayi and Samuel Orim Orim, 2020).

In Ghana, Cote d'Ivoire and other west part of Africa children with intellectual disability typically Down syndrome referred to as "snake children". Traditionally these children were not allowed to live and killed before the age of 5 years as they were considered products of displeased sprits. Research conducted by Bayat in 2014, on the killing and abuse of the snake children in Ghana and Cote d'Ivoire revealed although these children are not being killed in the present day, there is evidence that they and their families are still being stigmatized and discriminated against (Bayat, 2014). Also, in Uganda children with Down syndrome tends to be excluded by the education system. These negative attitude and cultural negativities towards children with Down syndrome and their family stigmatizing them from the society. Several research studies identified that parents with Down syndrome experience higher levels of social isolation. In their studies they were found that a majority had few supportive friends or neighbors and most were socially isolated from their local communities. They also found that support mainly came from their families and that if such support broke down, mothers were particularly vulnerable (McConnell & Llewellyn, 2002). However today we are becoming more and more modern in terms of technology and everyday life, in terms of thinking, there are still some of us who are trapped in ancient thought. They still see special children as a burden or a nuisance in society. Many of the members of the community around us are unaware of the disorder that children with Down syndrome have. They do not realize that affected children look just like other normal children from the outside. Their interior is very different. Because of this lack of awareness, they are prone to misunderstandings. Due to such misconceptions, society has moved away from families with such kind of ID.

As a result of their lack of information, Ethiopian parents, according to studies by Amakelew, Daniel, and Fasikawit (2000), feel uneasy and guilty since they believe they are responsible for their child's condition. They look for flaws in themselves that may have created impairment in their children, making them feel ashamed of their children and causing them to hide them from friends and neighbors. Parents face a new psychological problem as they gain more information and experience with their children's problems throughout time. They experience guilt that will never go away and will remain a part of the parent's emotional life for failing to recognize the problem with the children in a timely manner (Getnet, 2013)

2.5.2 Psychological challenges of parents having a child with Down syndrome

Many studies have been conducted and shows that more psychological support is provided for the affected children however parents do not receive adequate support in terms of psychological and emotional support from the moment parents get to know about their children diagnosis. Parents of children with Down syndrome have been found to frequently experience very high stress levels. High stress in parents can be a result of other stressors such as a history of abuse, low socio-economic status, stigmatization, a history of failure, unemployment, lack of support and social isolation. Increased demand for support and care can affect the overall well-being of caregivers (Nes...etal, .2014).

Studies show that parents specially mothers of a child with down syndrome experiencing physical health problem (Brehaut, J. C Kohen, D. E. Garner R. E. Miller, A. R. Lach, L. M., Klassen, A. F., & Rosenbaum, P. L., 2009), psychological distress and adjustment problems, increased risk for clinical depression, and lower levels of life satisfaction compared to mothers of children without disabilities (Nes, R. B., Røysamb, E., Hauge, L. J., Kornstad, T., Landolt, M. A., Irgens, L. M., . . ., 2014). Consequently, stress and anxiety are the common psychological challenges to these mothers raising a child with disability due to inability of children to express their feeling, future of their child, feeling of sorrow and who will take care if something happens to them.

2.5.3 Economic challenges of parents having a child with Down syndrome

Regardless of socioeconomic status prior to their birth, families of children with disabilities or chronic health conditions such as Down syndrome are likely to experience some degree of economic disadvantage as a result of having an affected child (Emerson, 2007). This might occur for either of two reasons. To begin with, caring for a child with chronic health conditions or disabilities can negatively affect family finances resulting from increased out-of-pocket costs associated with increased need for medical and developmental services. The cost of treatment, medicine and therapy is not cheap. Parents need to make sacrifices to provide enough money for their child to receive good treatment. But there are still parents who can't afford it. In addition, caring for an affected child can lead to reduced family income if one or both parents reduce the amount of time, they spend working in order to provide caregiving services. Even if parents do not reduce hours of paid employment, they may still feel financial pressure as a result of out-of-pocket expenses related to their child's condition and increased use of purchased services.

2.5.4 Adaptive Coping Strategies of parents raising a child with Down syndrome

Coping styles are defined as ways of responding in stressful situations (Strelau, 2005). Coping strategies, in turn, are specific reactions that an individual undertakes or activates, depending on a specific stressful situation. Parents coping strategies are more related to the resource to which they have access without these resource parents are vulnerable and more likely to experience higher level of stress. In this sense, Endler and Parker (1990) distinguished three major categories of coping styles: (1) problem-oriented coping, the style of coping with stress involving directly solving the problem or changing the source of stress; (2) emotion-oriented coping – the style, which is typical of the behaviors of people who, in stressful situation tend to focus on themselves and their own emotional experiences; and (3) avoidance-oriented, when an individual does not aim at confrontation with the problem, but tends to avoid thinking and experiencing that situation (Endler and Parker, 1990). Parental adaptation to a child with Down syndrome has also been studied extensively in relation to parental well-being, especially the psychological reactions of parents. Many studies on parental adaptation to a child with Down syndrome have focused primarily on stress.

It is believed that social support is an integral piece of coping with the stress of having a child with Down syndrome. Social support moderator of stress for parents of children with DS. Support can help parents cope by meeting their emotional, practical and information need (Matthew Altiere & Von Kluge, 2008). Other positive coping strategies included participation in religious and other individual activities. A popular negative coping mechanism was the family's withdrawal from other family members, friends, and society. In addition, families of children with Down syndrome were less likely to engage in social and recreational activities. McCubbin and Patterson (1981) describe some internal and external coping strategies. Internal coping strategies are when an individual change one's view of the situation. Family members sometimes hold on to the hope that the difficulties will go away on their own. In families with a kid who has Down syndrome, this is not a suitable coping method. Even if the child's functioning improves with time, some symptoms will always be there. One internal coping mechanism studied in Gill and Harris' (1991) research is commitment to a set of values. This includes one's sense of purposefulness and one's adherence to a set of philosophical and/or religious values.

Social support, spiritual support, and institutional support (community resources such as doctors and teachers) were among the external coping techniques developed by McCubbin and Patterson (1981). Social support is the most well researched external coping method. These external coping techniques may be the most crucial for families of children with autism, yet finding good support networks can be difficult.

A research on caregiver strain and coping among parents of children with learning difficulties was undertaken by Kenny and McGilloway (2007). There were 24 moms and 8 fathers in the sample. Caregivers' stress, everyday routines, support, and coping mechanisms were all discussed with the participants. According to Kenny and McGilloway, two-thirds of the participants received professional aid to deal more effectively. The participants also stated that having support from their child's school helped them deal more effectively. External sources of assistance are clearly important for parents living with a kid with a disability. Similarly, Angela (2013) found that parents found the Jamaica Autism Support Association (JASA) to be a significant source of support in raising their child, and that they were able to connect with other parents raising children on the spectrum through a support group or parent connection network at the center. Participants also noted that their child's presence at a center gave daily respite and the opportunity to access the counseling services given by the staff social workers, according to Gray research (Gray, 2006). Some parents choose to isolate themselves instead of facing the frustration of taking their child out in public. Relatives of ID children are frequently described by their parents as cold, aloof, and unhelpful (Schall, 2000). The combination of rejection from family members and stigma experienced by community members adds to the difficulty faced by families of children with ID. Some parents, on the other hand, report finding friends who accept their child's LD and assist them in leading regular social lives (Gray, 2006).

2.6 Theoretical Framework

For the purpose of this study, I used an ecological systems theoretical framework developed by Bronfenbrenner (1979). According to this hypothesis, the contexts or circumstances in which children grow have a significant impact on their development. As a result, it will be critical to understand how environmental concerns aid in developing the emotional and physical well-being of families of children with down syndrome as it relates to the child's development, including parent participation and other ecosystems. More specifically, Bronfenbrenner (1979) claimed that there are five important systems (the microsystem, mesosystem, exosystem, macrosystem, and the chronosystem) that influence and are influenced by the child's behavior and the most important system is the family which includes parent-child subsystems.

Bronfenbrenner microsystem is the first domain of emotions, those that are found within the family are central to a child's development. As the child matures the range of emotion grows to include the influences of the expanding environment. Here, culture and other external forces can influence the development of emotions such as fear of strangers, shame, and romantic love. In the family, school, and community, the child with intellectual disability interact with diverse microsystem structures and processes. Mesosystem is the layer that encompasses the connection between two or more microsystems structures of the child's (e.g., the family and the school, peer and family, family and community) that affects the child. At the meso level where children with developmental disorders and their families interact with institutions such as schools and social service agencies transpersonal factors, family, and organizational dynamics influences the child's quality of life (Ferguson, 2002). Exosystem is the third level of the ecosystem which referred as the wider social system in which the child does not directly function but has an impact on their development by interacting with some structure in their microsystem (Berk, 2000). The child may not be directly involved at this level, but does feel the positive or negative force involved in their system. The exosystem, which comprises not just bigger social institutions like community support and health services, but also other structures like the world of work and mass media that function on the layer, has other more remote relationships that indirectly affect the child with autism and the parent (Petra, 2012). The macrosystem refers to the broader sociocultural backdrop, which include convention, laws, cultural values, the economy, and the government. Each system has roles, conventions and rules that influence an individual growth (Ryan, 2001). Therefore, an intervention programs should pay particular attention to the culture and lifestyles of families raising children with special needs at the macro system level and enhance parenting quality of low-income, racial and ethnic minority caregivers who are often overburdened and feel helpless because the intervention programs and strategies are not consonant with their culture (Algood, Cynthia and Hong, 2013). Lastly, the chronosystem is the way environmental impacts over time affect the individual. It includes the transitions and shifts in one's lifespan. This may also involve the socio-historical contexts that may influence a person. (Such As., generational influences).

The ecological theory views disability not just as a medical condition, but also as one that is strongly linked to a variety of social circumstances that influence how a particular impairment is perceived in society. It also provided a context to explore the lives of parents’ as it encompasses various systems that directly and indirectly influences the children and their family.

CHAPTER 3

RESEARCH METHODOLGY

In this chapter research methodology are discussed in detail. Hence, research design, data type and source, sampling technique and sample size determination, data collection procedure, method of data analysis will be discussed.

3.1 Study design

Research designs are plans and the procedure for research that plan the decisions from broad assumptions to detailed methods of data collection and analysis (Creswell, 2009). This study was employed qualitative research design to explore in detail and answer the above-mentioned research questions. The qualitative method was selected for this study because it helped to acquire "in-depth understanding about a certain phenomenon through exploration instead of measurement (Bernard, 2008). Qualitative approach provides non-numerical data in the form of interview response, audio and videotape recording, field notes etc. (Lundeby, 2008). Therefore, it is very important to use a variety of methods in order to collect comprehensive data such as in-depth individual interview, focus group discussion, observation and key informant interview was employed. Information regarding personal challenges in raising a child with such kind of may be sensitive in nature and affect individuals on a personal level. Therefore, the researchers utilized a phenomenological research design in order to obtain the meaning of these personal challenges as experienced by parents. This design allowed parents to reflect on and share their life world as it relates to the learning disabilities of their children to analyze the data that was gathered through an in depth interview in line with the research questions of the study the researcher decided to use a descriptive approach in particular interpretative phenomenological data analysis method which is interrelated with the research design.

3.2 Study population

In this study the researcher will seek to understand and describe the experience, challenges and stress faced by parents in raising children with down syndrome, the study population was Addis Ababa city at Ethiopian Evangelical Church Mekaneyesus Center for Mentally Challenged Children. Ethiopian Evangelical Church Mekaneyesus Center for Mentally Challenged Children is a non-governmental organization established in 1986 to provide these children with an education that meets their special needs. Currently, the Center provides support for 400 children with disabilities (Intellectual disabilities, Autism Spectrum Disorder, Down syndrome, Deaf/Hearing Impairment, Visual Impairment, Cerebral Pals and Epilepsy), out of 400, 125 children have Down syndrome. The study was conducted on family having a child with down syndrome at pre-vocational and vocational class. The aim of the institution also includes enhancing the quality of children with intellectual and multiple disability. In addition to this the center provide awareness raising training for their families and guardians on how to manage and handle the children. Beneficiaries of the center are from diverse religious backgrounds and the function of the center is independent from the church-based services; however, the management system and financial support are under the church. Moreover, since it is the capital of the country, families having children with Down syndrome can access it which will give the researcher chance to communicate families from different places.

3.3 Sample size and sampling techniques

Ethiopian Evangelical Mekane Eyesus Church Center for mentally challenged children is selected purposely since the city is the capital of the country and it is one of the senior organizations to adopt mentally challenged children with the aim of enhancing the quality of life of children with such kind of intellectual disability. Moreover, the center works in creating an awareness on their family by preparing different training program. In order to get more relevant data about the lived experience and stress of parents in raising a child with down syndrome among the user on the organization, the age of children with the condition is very important to get satisfied information about the challenge of having children with down syndrome. Accordingly, parent who have a child with Down syndrome as minimum of 16 years were selected through purposive sampling technique. Purposive sampling technique prefer to select the informants carefully so that their in-depth interview can give an optimal insight of the study. It is a non-probability sampling method. This sampling method was chosen for this study because it offered promise with respect to gathering real experiences, emotions, and attitudes from parents faced with caring for a child with Down syndrome. For this study, a total of 25 participants were interviewed. However, determining about sample size in qualitative study was difficult because it depends on information saturation, Charmaz (2006) suggested 20-30 participants develop a well-saturated theory. For in-depth interview part, 12 parents of having a child with DS will be participate. Other 8 parents will be involved in two Focus group discussion. In addition, 3 care giver and 2 program facilitators will be interviewed. Generally, a total of 25 sample individual were participated.

3.4 Data collection methods

This study employs in-depth interviews and focus group discussion. These methods were selected by the research because, they have been found to be more appropriate to gather deep information on the subject and allow flexibility when running different session of interviews, which help to clarify unclear question and pick important cases needed for the research.

3.4.1 In-depth interview

An in-depth interview is one of the primary methods of data collection used in qualitative research. The in-depth interview helps the researcher to explore and deeply understand the situation. In addition, it helps to enable the research participants to talk and express their feelings and opinion freely. An in-depth semi structured interview guide will prepare in a way that addresses the objectives of the study. It was conducted with families who have children with Down syndrome until saturation is reached. The interview questions included items considering general information about the child, the parent's reaction during and after hearing the initial diagnosis, if/how Autism has changed the parent's lives, the amount of psychological and social challenges that was experienced after the diagnosis (if any) and methods that were used to cope with the challenges (if any). To make the interview information rich and understandable, open ended questions were utilized to allow participants to react in their own terms rather than constraining them to choose from predefined responses. The interview questions were written in Amharic because it is a language that both the participants and the interviewer understand. Moreover, all the questions in the interviews were directly linked to the research's aim and covered all aspects of the topic.

3.4.2 Focus Group Discussion

The focus group discussion was another qualitative data collection method used in this study. Focus group discussion was selected to get a wide range of responses from different individuals selected from parent and to look the issue in different dimensions through group interaction. Focus group discussion is a valuable method when the researcher lacks substantial information about the subjects. It provides “a rich and detailed set of data about perceptions, thoughts, feelings and impressions of people in their own words” (Stewart & Shamdasani, 1990)

3.4.3 Observation

Observation is one of the tools utilize to generate data based on the observation checklist. Both the interview, focus group discussion and other related activities gave the researcher an opportunity to observe the overall situation of the family.

3.5 Data collection tools

Different methods select to gather relevant data from various sources. The instrument selected for the study was interview question, focus group discussion guide question, and observation checklist. In order to ensure the rigor of this study audio recording was applied at the time of interview and FGD. It provided a more accurate representation of an interview and focus group discussion than any other method and allowed for cross-checking if any notes were missed throughout the interview from the researcher.

3.7 Data analysis technique

The interview was be held in local language of participant, Amharic and transcription were made in English after carefully listening to the Amharic interview. The collected data was transcribed and analyzed by me. Prior to the analysis of the data, then I perform transcription, coding, and theme identification. Data were read and re-read in order to help the me immerse in to the data and find some interpretive cues from the statements of participants. Then, the data were coded by highlighting text with different writing style and making marginal commentaries that consists of paraphrase data, the links note between the data, and my own preliminary interpretations. This step was repeated and several themes were identified based on the annotations made. For the purpose of this study Interpretive phenomenological Analysis (IPA) was employed. IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences" (Smith et al., 2009). IPA seeks to understand the meanings individuals attach to human experience, and is concerned with exploring experience in its own terms ((Smith, L.E., Hong, J., Seltzer, M.M., Greenberg, J.S., Almeida, D.M. and Bishop, S.L, 2010)), it is an approach dedicated to glean individuals' direct experiences through encouraging respondents to tell their own story in their own words –participants are considered the experiential experts. Moreover, phenomenological analysis is an appropriate method of analysis where an issue is personal and it is able to contribute to understanding an area of interest through a deeper, more personal, individualized analysis. Therefore, IPA was selected for the present study as it was the suitable method of analyzing the in-depth meanings of participant’s experience.

CHAPTER 4

RESULT AND DISSCUSSION

4.1. Introduction

In this chapter, the findings from the data are presented combined with data analysis. This chapter is classified into two sections. The first section is about the socio-demographic characteristics of parents who participated in the study. The second section presented different themes that emerged from the collected data.

Background of the respondent

4.1.1 In-depth Interview with parents

The in-depth interview was conducted with twelve family members who were purposely selected from parents in the organization.

No	codes of parent	Age	Educational status of parents	occupation	Marital status	Age of child when diagnosed	Gender of the child	Current Age of child
1	P_1	42	Diploma	Private business	Divorced	when he was born	Male	22
2	P_2	38	8th Grade	-	Divorced	1 year and 7 months	Male	17
3	P_3	35	10th Grade	-	Married	1 years	Male	16
4	P_4	45	6th Grade	Small Business	Married	13 years	Male	16
5	P_5	38	Degree in accounting	Accountant	Married	4 years and 6 months	Female	18
6	P_6	34	8th Grade	Cleaning	Divorced	3 years	Female	17

				leady				
7	P_7	41	6thGrade	-	Married	2 years and 8 months	Female	19
8	P_8	36	Diploma in Accounting	Daily labor	Divorced	3 years	Female	16
9	P_9	48	10th Grade	Driver	Married	4 years	Male	21
10	P_{10}	39	10the Grade	-	Divorced	1 year and 4 months	Female	17
11	P_{11}	47	Diploma in Teaching	Assistant teacher	Married	6 months	Male	16
12	P_{12}	51	Degree in management	Private business	Married	2 years and 5 months	Female	17

Table 1. Profile of the informant

4.1.2 Focus Group Discussion with parents

Two focus group discussions were conducted with parents of a child with down syndrome from pre vocational and vocational (life and skill training) class. The number of participants in each focus group discussions was four. So, a total number of eight parents were participated in the discussion.

4.1.3 Key Informants Interview with program coordinating staff and care provider

Semi-structured interview was made with project coordinating staff member who work closely with the children and family supporting program. Two service care providers have been interviewed from the organization. They were selected by considering the period of time they were employed in the institute in order to get full information about the children condition as well as family response.

4.2 The Themes identified about the Experience appraisal, stress and adaption of parents raising children diagnosed with Down syndrome.

By reading a data set (such as transcripts from in depth interviews or focus groups), and identifying patterns in meaning across the data to derive themes. The main issues which came out of the study were categorized under the following five major themes:

(1) Parent initial reaction to the diagnosis of syndrome

(2) Social challenges

(3) Psychological challenges

(4) Economic burden and

(5) Coping method of parents having a child with Down syndrome

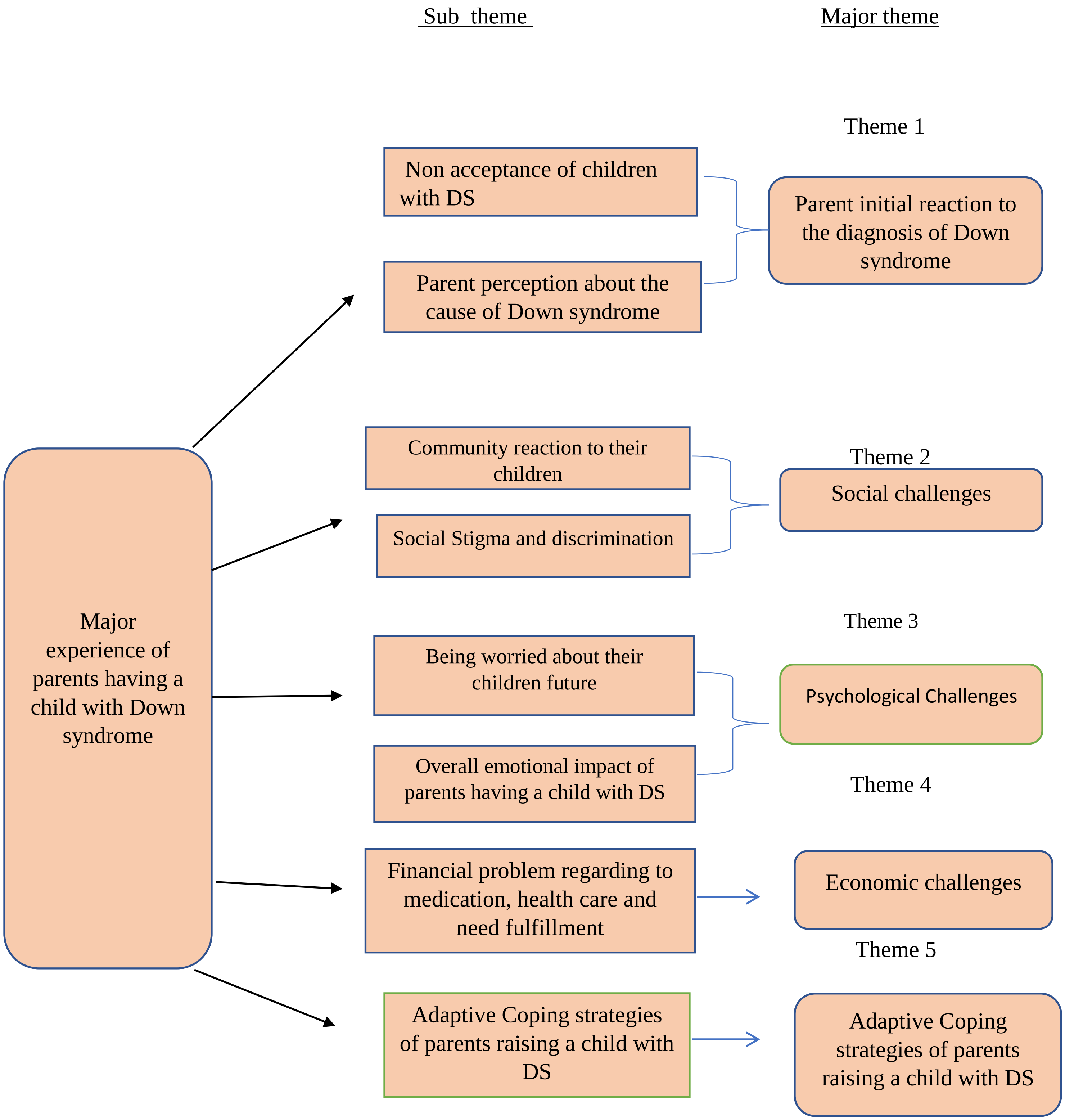

Figure 2. Themes and subthemes that have been derived from the study result

4.2.1 Parent initial reaction to the diagnosis of Down syndrome

When parents are informed that their newborn has DS, they initially deny in accepting the diagnosis and express anger and fear in reaction to coming to know about the disability.

4.2.1.1 Non acceptance of children with DS

The common initial reaction was lack of acceptance, denial to the extent that even a few parents of children with DS still had hope that one day their child would be free of this disorder. They also had feelings of hopelessness because of the things that the child cannot do things independently and often felt like crying. Later on, they are start to find help with DS diagnosis and visiting many doctors to deal with the frequent challenges that DS children face. The following two parents stated about their first respond when they informed that their children have DS.

> *"At the time, I was giving birth at home. In our village, there is no specific follow-up for pregnant women at that time…. My child seemed to be a distinct creature when he was two years old. Then I made the decision to consult a doctor. It was difficult for me to accept what the doctor said. Then I inquired about Down syndrome with the doctor".* (IDI, p11)

Similarly, another mother had a perception that her child's disability was due to the curse from God.

> *"I've never heard of this situation and never known anyone who has. Since my son went to the clinic and learned about his illness from the doctor, I've thought of myself as a cursed woman."* (IDI, p6)

Instead of embracing the reality of their child situation, few parents live their lives in the hope that one day a child will be cured from this disorder.

> *"My son is now 16 years old and until he was 14, I couldn't accept he had such a problem. I've always hoped that one day my child would be free from this condition and be able to live like any other child"* (IDI, p3)

The response above indicate that the majority of participant immediate reaction after informing that their child has Down syndrome shock, disappointment, anger, disbelief and guilty feeling.

They had no knowledge of Down syndrome, not even its name. Some of them seek clarifications from health professionals in order to gain a better understanding of the child condition. A few parents still have a hope for the normality of their children and pray fervently. This study in line with the finding of several studies conducted around the world, which indicate that parents had feelings of despair, sadness, or overwhelm when learning of their children's diagnosis (Angela, 2013 and Lindsey). Anger, disappointment, and shame reactions result from the fact that the child is not the ideal child that the parent anticipated. The child is unable to fulfill the hopes and ambitions he/she was expected to.

4.2.1.2 Parent perception about the cause of Down syndrome

According to my observations, many parents were unaware of the cause of DS and they were informed very late. Advice and explanations received from family members and neighbors altered the perspectives of some Parents. Family members or society attempted to explain how the children's disabilities could be caused by an evil eye spirit. The perception of some parents was influenced by advices and explanations they received from family members and neighbors.

> *"Because his father's family in the countryside follows and claims in witchcraft, the first thing that came to my mind was an evil spirit. In addition, I sought advice from a neighbor about the situation, and they continually warned me that my child was possessed by an evil spirit."* (IDI, p7)

Parents thought as they have been cursed by God to have a child with Down syndrome as their explanation for the cause of their children's because they didn't do anything wrong during their pregnancy time

> *"Because I did nothing wrong during pregnancy, I think it was God's wrath that caused this to happen to my son, so every day I went to church and asked God "why did you want this happen to my son? Why you cursed me like this?" .... I prayed always to take this curse away from me.* (IDI, p6)

The above sentiments from the participant indicate that, many parents are unaware what an intellectual disability involves and many of them will have various perception and speculations about the cause of this disorder. This finding is consistent with the findings of Chernet and Opdal, (2007) that shows most of the parents in their study attributed the cause of the children's disability to God. These beliefs also similar to the findings of studies from other parts of Ethiopia and Africa (Tilahun, Fekadu, Tekola, & Hoekstra, 2016; Mashudat, et.al ,2013; Gona et.al 2015), which showed the reason of parents for intellectual disability like DS including witchcraft, evil spirits and curses, enemies, and action of the devil, and evil eye by parents and other segments of a society. However, this finding is in contrast to other western studies conducted in UK (Russell & Norwich's, 2011), in US (Harrington, Patrick, Edwards, and Brand, 2006), where the majority of parents reported scientific explanation as the underlying cause of ID, participants in their study mentioned that they are not aware of the exact causes of ID but they mentioned biological or environmental causes including immunizations, genetic predisposition, labor complications, genetic inheritance, head trauma and organic defect in the brain and viral infection during pregnancy as possible causes for their children's developmental disability.

> *"I can't quit wondering whether there was something I did wrong to cause this happen to my child. I was trying to recall the duration of my pregnancy, beginning with the first month." (*IDI, p7)

Minority of parent's experience stresses during pregnancy and believes this stress was affecting their fetus. So, they believe that those events cause DS. This is all part of the process of figuring out what happened. parents also stated that lack of understanding regarding the cause of Down syndrome was a factor in the challenge they faced, including feeling of helplessness and denial after informing that their children had Down syndrome. Other studies (e.g., Ashely, 2012; Maggie, 2010) revealed that parent's comprehension of the disorder was very limited and that this lack of knowledge led to first reaction of fear, denial and shock on the part of parents.

4.2.2 Social challenges

4.2.2.1 Community reaction to their children

The biggest issue for parents of children with DS was related to the community: inappropriate community member behavior, a lack of knowledge and suitable education about DS in society, and finally, a lack of adequate community infrastructure to help the parents of these children. Almost the majority of parents mentioned lack of awareness in the community about genetic diseases such as DS.

> *"The mother of a 17-year-old child described "It's a little better now, but formerly, people treated children with disabilities quite badly; so, parents chose to take their children to the country side."* (IDI, p2)

The other two participant parents were also stated about community wrong attitude towards their children to a certain intellectual disability.

> *"Personally, the reaction of the community was more challenging for me than my son difficult situation. They do not have a good attitude towards me and my child.* (IDI, p1)
>
> *"I am leaving in the community that does not understand you. My daughter claims she doesn't touch anybody and doesn't want to touched by others, but the community thinks she will hit and push their child so they are not allowed their children to play with her"* (FGD P3)

The expression of above indicate that because of societal misinterpretation of the intellectual disability, when parents know that their child has down syndrome, they become disturbed and react by hiding the child from the community. It also one of the reasons why we don't know the actual frequency and incidence rate of Down syndrome in our country. Due to lack of knowledge about Down syndrome by community, family face a lot of challenges. For instance, in study by Lori (2008), participant reported that taking a child with ID out as a source of stress for parents because people stare, make negative comments may occur due to lack of knowledge about down syndrome. In line with this a qualitative research by Kristen (2008), participant reported a feeling of being negatively evaluated by the community as a result of lack of awareness of ID in society at large.

4.2.2.2 Social stigma and discrimination

Most parents face the difficult task of telling others about the baby, and usually quite soon after they have been given the diagnosis. It is not easy to say 'my baby has Down syndrome. Majority of parents complained about how difficult it is to make social visits to relatives and involve in social activity due to wrong perception of community about their children. That made many parents feel socially isolated. There is also sadness on the child's siblings. Moreover, the unavailability of community services and lack of awareness about Down syndrome makes the thing more challenging for the family. Parents also mentioned that having a child with DS affected their social lives to the extent that it was not easy for them to participate in a family event.

The majority of parents stated that they had been subjected to stigma and that they were obliged to spend more time at home rather than go out. Negative social perceptions about mental illness and intellectual disability were among the causes of stigma.

> *"You realize that other people are staring at you strangely, like if we're from another planet. I believe that because society does not accept both me and my child, my inner self has changed; I hide the fact that my child has Down syndrome and requires special treatment from others."* (IDI, p3)

One of the participant mentioned that the difference between society understandings in developed country and Ethiopia

> *"I gave a birth to my son, when I was in Saudi Arabia. There were a lot of Down syndrome afflicted kids in that town. The community, in the other hand, was ecstatic with the situation. As the result, they would treat them as they were any other individual…. When we return to our nation, however, a society perception of these youngsters is entirely altered. Such children are not allowed to join and play with their children. They are so hated and marginalized by the community."* (IDI, p1)

> *"I don't care what people say about me, but when it comes to my child, I want him to be able to grow up freely. My wife on the other hand does not want him to get close to people because she is afraid that people will say or exclude him for me. It is because people don't have an awareness and realize it's a health condition…. they believe it is because you've done something wrong."* (FGD, p5)

From the above statement, it clears that there is social stigma on both children and parents. The stigma kept parents from participating in their communities and it had an impact on their lives other than caring for their children with Down syndrome. According to the studies, in Africa children with ID like DS seen as a source of shame on the family by society. As a result individuals with Down syndrome and their families are frequently confronted with negative attitudes, avoidance, rejection as well as negative and offensive comments leading families to hide the affected child from the society and it’s a major sources of stress for parents (Mashudat A. Bello-Mojeed, Dr. Muideen Owolabi Bakare and Dr. Kerim Munir, 2013)

> *“What I lost because of my child condition is not just the opportunity to participate in the community but also I had no one to talk to about my anxiety. This situation has made me to feel anxious and lonely…. There is nothing harder than being alone in your life, even the most difficult problem became easier when we talked to people freely. “(*FGD P1)

One of the participants on the above stated that emotional isolation was much more difficult for him in the process of raising a child with Down syndrome than social isolation. As research stated by, Cunningham (2006) parents may isolated both socially and emotionally from the community Social isolation refers to inability to get out and do things because of the child condition whereas emotional isolation is when parents feel they have no one with whom to share their worries and concerns with, and no one who understands what it is like to have a child with a down syndrome.

One of the participants from the caregiver also mentioned what she observes in her serving years.

> *“I had served in this organization for the last 25 years…. Some times in addition to the parents even for those of us who are engaged in this field work, the community does not have a positive attitude…. It takes a lot of work in the community to change this misconception.”*

4.2.3 Psychological challenges

The parents spoke of several psychological challenges they endure when raising their children. Psychologically, parents experience emotions such as fear, worry, depression, anxiety, and guilt. For most children with Down syndrome, the stress begins when they suspect that their child has a developmental delay. They may also consistently compare their child with normal children and blame themselves. Some of the parents blamed their stress on having a lot of responsibilities in terms of daycare. Some of the parents blamed their anxiety on financial difficulties. Others blamed their anxiety on the child's inability to communicate.

> “*I have not been a healthy person for years… I have nothing in me, I have no energy*. *The economic burden of managing the rest of family, providing medication treatment for my*

> *son, perspective of close relatives and community towards my child frustrating experience for me in my life…"* (FGD p7)

Another participant from FGD also added:

> *"When I speak friends or family, I couldn't control my emotion and fear that in most cases my tears exceed me before I began to express my thoughts, feelings, arguments or any idea that I want to say for others. This bad experience irritated me in the whole days of my past especially in the first time when I know my child had Down syndrome."* (FGD, p6)

The above quote clearly indicates that parents who has child with Down syndrome experience higher levels of stress compared to parents with children with a normal development. This include difficulties with emotional well-being as well as mental health issues (e.g. depression). Most of the psychological challenges of parents having a child with Down syndrome related to it brings extra things to deal with, such as coming to terms with the diagnosis, coping with any medical problems, selecting schools, arranging future care and overcoming community reaction. The child usually makes extra demands on time and supervision and so when other stressors arise, they can interact with this and together increase the stress experienced (Cunningham C. , 1996). Other Factors associated with parental stress is mental and emotional well-being of children, requirement of extra effort in daily routine task, sleeping difficulty or insomnia and societal discrimination towards their children due to the circumstance, some parents feel guilty because they believe they may have contributed to the disorder's development. A few parents were angry because they had a bad parenting experience (Gobrial E. , 2018). The stressors indicated above appear to be more acute for families with DS children, making their life more difficult and causing daily difficulties and hindrances.

One of the parents admitted to how having marital issues as a result of having a kid with Down syndrome messed up their well-being.

> *"After I gave birth to my baby, I experienced a lot of stress in my life since my husband couldn't handle the pressure and blamed me for what happened to my child. He didn't want to see me, he didn't have a time for his family, and he told me over and over that he despised the house because of me. In addition to my husband erratic behavior, my son's*

> *illness, as well as the responsibilities I bear, make me very concerned and miserable." (FGD, p3)*

Mostly mothers of a child are exposed to high level of stress because of her responsibility of providing care for her child. For instance, a study by Aynalem (2014) indicate that the impact of ID on Ethiopian mothers is expressively visible on their daily routine and life experience and they do not feel free to talk about their children openly instead they feel guilty are ashamed of their children with disability.

4.2.3.1 Being worried about their children future

The participants had shared concerns with regard to their children future. They had several common questions: What will happen to my child in the future? Who will take care of him/her after my death? Can s/he have an independent life in society? Two parents reported constant worry about the long-term impact of Down syndrome on the child's future.

> *"You start to be concerned about what will happen to her in the long-term. I'm worried about how my child will fit in with the rest of the world; will she be able to live independently?"* (IDI, p2)

Another participant also added that:

> *"When I think of the future, I get depressed and frustrated, these children are deprived of the attention of their close relatives, community and the government. So, when I think about my son future, I always feel sad and anxious."* (IDI, p10)

The current finding shows that when parents of children with Down syndrome think about the future, they are especially concerned about their children health's, well-being and the meaning of life as well as higher pessimism, helplessness, and more concern about his/her social relationship. Similarly, research done by Meron (2006) state that inability of children to communicate their feelings, the future of the child and who will take care of them if something happens to them, stress is a common psychological difficulty for parents raising a child with down syndrome (Meron, 2006). In consistent with the current research finding other previous research on the worry and stress of parents of children with down syndrome revealed that the child future quality of life, self-reliance, education, relationship with others, and work or financial prospects were all linked to the parents anxiety specially mothers (Ilias, Liaw, Cornish,Park, Golden, K.J, 2017)

4.2.3.2 Overall emotional impact of parents having a child with Down syndrome

Parents experience a wide range of emotions with the birth of a child with DS. Participants cited shock and astonishment as a result of hearing the bad news from the doctor or seeing the baby's appearance. They also mentioned heartbreak, worry, anxiety, denial of reality, and frustration. They also had feeling of hopelessness because of the things that their child cannot do things by his/her independently.

> *"One of the male participants said: "I did not believe my eyes when I saw my baby in the hospital, I felt thunderstruck for a moment because he was my first child. For my wife, it was more painful and distressing. All mothers wish giving birth to a healthy child after nine months of pregnancy with suffering and difficulty. However, since my son was born, we experienced more discomfort, anxiety, and stress instead of being happy*". (IDI, p5)

One of the participants said that: Sometimes, I cried all day and night when I think that my future life is filled with adversity and blamed herself.

> *"I was convinced that I had done something wrong; I blamed myself for my child's abnormal behavior. I was depressed for a long period after learning of the diagnosis, and I cried every night before going to sleep."* (IDI, p7)

Another participant highlighted that she was blamed and insulted by her husband for the child's disorder

> *"I suffered a lot. Even my husband assumed that as if I created her with my hands or he think like I am the reason for my son disorder. I had faced a lot of challenges after he walked away."* (IDI, p2)

In terms of emotional difficulties, the findings reveal that the parents have a high level of stress and hostility. The severity of depression can be measured by how depressed you feel on a daily basis, as well as your ability to cope with stressful situations. These emotional difficulties could be caused by "complicated interplay between internal and external circumstances, such as dealing with their children" and "interactions with others outside the family (Hyassat, 2015).

An additional study also found the divorce rate ten times larger in the families with a disabled child than in the general population (McCormack, 2009). Such disability can affect a couple marriage in variety of ways, including creating strong parental feelings and fertile ground for conflict (Featherstone, 1999). Marital disruption and family dysfunction increased stress for families of children with Down syndrome. Furthermore, several prospective studies have found that child behavior problems predict later parent stress, and this may mediate the relationship between child behavior problems and family dysfunction (Baker *et al*., 2003; Eisenhower *et al*., 2013 ;) which finally affect the emotional well-being of parents.

4.2.4 Economic burden

Parents also mentioned financial difficulties in raising their children with Down syndrome as a challenge. Almost all of the parent noted that their families face substantial financial difficulties. Particularly, families with only one working parent or women who were separated from their husbands felt much more difficult to live. Throughout their lives, children with Down syndrome face a variety of ailments. They are frequently born with a variety of physical and mental abnormalities that necessitate extra attention and medical treatment.

4.2.3.3 Financial problem regarding to medication, health care and need fulfilment

Most of the mothers were single and unemployed without the active presence of the father in the child's life. One of the participants discussed the financial strains she had as a single mother, as well as her irritation with her child's father, who refuses to assist financially. She spoke about the financial challenges in caring for her son and the difficulty in caring for him and how it impedes her ability to work outside the home.

> *"I divorced my husband as soon as she was born. After my spouse and I broke up, I was responsible for all of the outdoor activities as well as my child's fundamental necessities. I keep my house in order by running a little business, such as baking injera and doing laundry. However, I only make a tiny amount of money from this job, I am unable to meet my daughter needs."* (IDI, p8)

This challenge is also mentioned by project coordinator as the main difficulties' parents face in the process of raising their children.

> "*Most of the children come from poor families, often the mothers are a single parent. Parent specially mothers of the children are not able to work due to the care they have to give to the children…because of this parent cannot meet the basic need of children properly"*

Another significant issue for parents was the difficulty in obtaining various facilities and services for their children. Due to a dearth of inexpensive schools, all of the parents were continuously concerned about funding their children's school fees, as well as the cost of medication and treatment. Parents indicated that however education at governmental schools is fully free but registration, uniforms and educational materials such as books have some costs. Moreover, schools lack appropriate care and treatment for children from the school community which causes grievances and disappointment between parents. Almost all the families had difficulties acquiring the extra income to pay for the therapies the child needed.

> *"We'd have to pay a taxi to go and a taxi to come back, to buy medicines for my daughter, milk...sometimes it wasn't possible to arrange therapy at the social security and when we had a bit of money, we'd pay for private therapy…but we couldn't always"* (IDI, p2)

> *"I work, but my wife quit her job and stayed at home with my child; I don't think she will be able to work for a long time. Currently, I am responsible for all expenses, including medical, educational, and speech therapy fees, as well as the bills of two other children."* (IDI, p5)

As the above research finding show that parents' myth and misconception regarding the cause of children with Down syndrome, such as the belief that they are a curse from God or that an unfaithful wife is to blame, most marriage end soon after the birth of a child with Down Syndrome (Chilwalo, 2010). Due to the aforementioned superstition, lone mothers are frequently forced to shoulder the burden of child care for children with DS. However, few parents live together after diagnosis of their child, all the responsibility rely completely on one partner's income while the other stayed at home to care for the child. As general parents are becoming more tired and experiencing a loss of leisure time as a result of child care and increased duty (Badger, 1996)

4.2.5 Adaptive Coping Strategies of parent raising a child with Down syndrome

Coping with medical difficulties, harassment and exclusion of their children by others, and disappointment with the child's capacity to reach adult strengths were the most significant challenges faced by families with DS children. Improved communication between parents, family, community, and the health system can increase the satisfaction and the well-being both of the children with DS and their parents (Marshall, 2014). As parents begin to value the child as a source of enrichment in family life, positive adaptations can develop.

> “*Since joining this center, I can state my child has entirely transformed from the beginning. They educate him suitable social interaction skills and appropriate behavior in various setting. The organization also program life sharing program for families which provide an opportunity to meet other parents who were in the same boat as myself”* (IDI, p3)

One of the FGD participants also mentioned that how having counseling sessions related to the condition as well as the challenge (including social, economic, emotional and health problems) with health care professional helps her to cope with the circumstance. She put a better communication with professional as a possible solution which can help to achieve more.

“

The parents reported that having social support from family, friends or organization helped them to accept and normalize their children condition. During this study, the researcher discovered that different technique utilized by parents to deal with social stigma and discrimination.

> *“I don’t socialize with my neighbors. To keep my mind safe and healthy, I don’t mix up with any one and instead sit at home with my child. Because I have not the ability to handle all those negative comment towards my child that’s why I isolate myself from any kind of social activity.”* (FGD, p4)

Some parents stated that they tried to cope with social stigma by disregarding unpleasant reaction from others. Similar results were presented by other studies which indicated the use of different mechanisms by parents of children with disability to deal with different circumstance; such as isolation, restricting public encounters, ignoring or reacting against such judgments through engagement with their children and with the environments surrounding their children; and confiding in their own parents, siblings, friends, and certain medical professionals regarding private matters (Hays and Butausk, 2018). Bayat (2007) indicated the most useful source of formal support for the participant parent seems to be parent support groups, where they feel free to discuss their concerns about rearing a child with disability without fear of being inspected.

> *"I spent most of my time by serving in the church. For my condition the most appropriate bible verse in the bible was "እግዛብሄርንም ለሚወዱት እንደ ሃሳቡም ለተጠሩት ነገር ሁሉ ለበጎ እንዲደረግ እናውቃለን" so I believe this condition happen to my daughter by the will of God, so he maybe has a big plan for her"* (IDI, p6)

Another participant from parents also added that:

> *"When I go to church and begin to pray frequently, my stress level gradually begins to decrease. I used to drink holy water, and I let my son do the same"* (FGD, p6)

> *"Even my families see it as a curse, which still sadness me because he is my first child. I tried to disregard what others say, but I tell myself that Allah gave me this child so that I may think he can give me courage to face all of the problems that have come my way."* (IDI, p2)

As stated in the above, some of the parents they engaged in spiritual beliefs to decrease the stress of themselves that came from managing their children. For these parent's faith serves as an important resource in coping (Nobrega and Oliveira , 2005). Accordingly, Gona *et al.* (2010) and Joachim and Robert (2012) found that when parents found themselves in a state of helplessness, they engaged in spiritual beliefs as faith and belief in God plays an important role in reduction of stress for parents with disabled children.

> *"I am not a medical professional but I like to read articles and book which is related to health. So, I was able to understand the nature of the disease and what can cause it. The fact that I learned from various source help me to cope with my child situation."* (FGD, P4)

Two of the participants from FGD stated that their own knowledge from a variety of sources including internet and other parents of children with the same problem help them to cope with associated problems of having a child with Down syndrome. Moreover, (Hossein et.al, 2013 and

Kirsten, 2008) both similarly stated that parent's education significantly can predict the level of parent's empowerment and participants acknowledged the value of learning from other parents as part of being able to get on with things. Gray, (2006) also demonstrated that participants reported the child's attendance at a center provided daily respite for them and the opportunity to make use of the counseling services provided by the staff social workers.

Research by other researcher confirms that Parents with higher levels of education and from higher socioeconomic backgrounds are more likely to recognize unusual developmental patterns and seek professional care. Furthermore, parents with higher education are less nervous, have more personal resource, have a better chance in labor market and encourage their children in learning new skills. Parental education also linked to measure of parental well-being, more effective dealing with challenges and burden associated with caring for the child with DS and as a result, lower dread intensity (Harstad, E.Huntington, N. J. Barbaresi, W, 2013).

CHAPTER 5

CONCLUSION AND RECOMMENDATION

5.1 Conclusion

Parents having children with Down syndrome experience financial, social, marital, psychological, and other obstacles, according to research. The costs of providing special education and medication are significant, which poses a financial barrier. Several parents especially mothers were also obliged to leave their occupations in order to care for their children. The family's monthly income was decrease as a result of this. In terms of social obstacles, parents find it difficult to participate in social activities. Both the child with Down syndrome and their parents face social stigma and prejudice as a result of religious and cultural views in the community. Reason for barriers to parents having a child with DS to participate in society, according to the participant parents and caregivers, was the society's perception about these children. Those children are viewed by the society as evil, the consequence of sin, or as a curse from God for misdeeds done by their parents. According to the result of studies economically, the majority of parents that participate are poor. This could be because they appear to spend more money to meet the needs of children with Down syndrome, such as acquiring educational materials, health care and other special need based on the severity of the problem. When one of them leaves employment to take care for their children, the problem become more challenging. Moreover, the parents also stated that they would be more mentally harmed as result of society attitude due to lack of awareness of Down syndrome and its related stigma. Parents also said that they used a variety of adaption strategies to deal with this difficult situation such as social support, engaging themselves in spiritual beliefs/ religion, isolating themselves from the society and self-education. This study sheds light on parental stress in families with children who have Down syndrome. A proper awareness training and advocacy program should be prepared and provided to parents as well as the community in order to decrease the stress of those families with Down syndrome. This leads to the next section which outlines some of the recommendations extracted from this study.

5.2 Recommendation

An extensive research should be done in the area of Down syndrome to help the affected individuals and their family to promote the concept in Ethiopia especially in rural area of the country. In developed societies the change towards a much more positive outlook has resulted in the provision of support services and a policy of inclusion in the community. Increasing guidance and support for parents, including education from birth and help with child management, which should: Help the children to become more skilled and independent, and reduce behavior problems Help parents avoid becoming isolated and making the child too dependent on them.

5.2.1 Implication for social work education and practice

The research finding has a lot of implication to all relevant the challenge of parents having a child with Down syndrome. Social work profession is concerned about the poor, voiceless, discriminated, oppressed, and for those who are living in continuous injustice. Taking these value and principle of a social work into consideration social work professionals work to facilitate the inclusion of socially excluded, dispossessed, vulnerable and at-risk groups of people and address and challenge barriers, inequalities and injustice that exist in a society by mobilizing individuals, families, groups, organizations and communities to enhance their well-being and problem-solving capacities (IFSW & IASSW, 2004). To achieve the above resolution, it needs the use of various types of intervention, advocacy and empowerment efforts.

However, family can also have difficulty understanding the diagnosis leading to feeling of misunderstanding and isolation, support group and others community resource serve as a strong support for parents in feeling understood and validated in their journey with other child who has DS. Often children with DS diagnosis will need special accommodation within the school setting. School social worker often are involved in setting up these service and work to support the student in his or her educational goals

Social worker can provide parent with support relating to emotional stress as well as resource to benefit the child with DS as well as the family. A holistic approach can be utilized by school social worker in supporting the family system. Social worker is able to provide the parent with education about the diagnosis, assessment and treatment options, support processing how to parent feels about the diagnosis and children.

5.2.2 Implication for the Government

It would be crucial if the Ethiopian government give a series of attention to parents of a children with Down syndrome through provision of educational, healthcare, intellectual disability and alternative day care service. Also, the government allocate resource to train professionals in order to facilitate effective diagnosis and early intervention for the children. This measure can largely reduce the concern and unpleasant experience of parents and improve their quality of life and mental health. Basically, the government sector can involve in the service giving program those are ministry of health, social welfare department and minster of education should work together for protecting their well-being and minimizing lack of knowledge in the society about the condition.

Developing policies and making decisions for addressing the challenges faced by the parents of having a child with Down syndrome. Creating a number of public centers for children with Down syndrome with the goal of offering free special education services to the youngsters. In such centers, highly qualified specialists must be hired.

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ANNEX: I

IN- depth interview and FGD guide

- Thank you for your cooperation
  1. Interviewer Name
  2. Date of interview
  3. Question identification number

Part I. Socio demographic information

1. ***Personal data of the participant***

a) Address: Worde: ______ kebele: ________

b) Age: ________

c) Sex: ____________

d) What is your occupation: _____________

f) What is your Marital Status: _________________________

g) Number of children: _______________

h) Age group of children with Down syndrome: ___________

2. ***Information of the Child***

a) Age___

b) Diagnostic age____

c) Sex ___

Part II Question

1) When did you first notice your child has Down syndrome?
2) What was your past awareness about such kind of intellectual disabilities?
3) What did you feel when you first informed about your children condition?
4) What are the most difficult aspects of parenting a child with Down syndrome?
5) How do you cope with the challenges of caring for a child with Down syndrome?
6) What do you notice about family, neighbor and society attitude towards your children with Down syndrome?

7) What are the social and other related problems you have faced when raising your children?
8) How do you express your relationship with the surrounding community?
9) How did you overcome challenge from the community?
10) If there is anything that is not covered in the questions above that you would like to explain more?

ANNEX: II

Amharic version of FGD and In-depth interview

- ሰለትብብርዎ አመሰግናለው

1. የመረጃ ሰብሳቢው ስም ________________________
2. ቃለመጠይቅ የተደረገበት ቀን ______________________
3. የቃለመጠይቅ መለያ ቁጥር ______________________

ክፍል 1 የተጠያቂው ማህበረሰባዊ እና ግለሰባዊ ሁኔታ

የተሳታፊው ግላዊ ማረጃ

1. አድራሻ፡ ___________ ወረዳ _____________ቀበሌ ________________
2. እድሜ _____________
3. ፆታ ________________
4. የተሰማራህበት/የተሰማራሽበት የስራ ዘርፍ ________________
5. የጋብቻ ሁኔታ ____________________
6. የተጠቂ ልጅዎ እድሜ ________________

የልጆች መረጃ

1. እድሜ _________________
2. በሽታው የተረጋገጠበት እድሜ _____________
3. ፆታ __________

ክፍል 2 ጥያቄ

1. ልጅዎ ዳወንሲንድረም እንዳለበት ለመጀመሪያ ጊዜ ያወቁት መቼ ነው?
2. ከዚህ በፊት ስለ አእምሮ እድገት ዉስንነት ያለዎት ግንዛቤ ወይንም እዉቀት ምን ይመስላል?

3. ስለ ልጅዎ ሁኔታ ለመጀመሪያ ጊዜ ሲያውቁ/ ሲሰሙ ምን ተሰማዎት?
4. ዳወን ሲንድሮም ያለበትን ልጅ የማሳደግ በጣም አስቸጋሪው ሁኔታ ምንድን ነው?
5. ዳወን ሲንድሮም ያለበት ልጅን በማሳደግ ረገድ የሚያጋጥሞትን ፈተናዎች እንዴት ይቋቋማሉ?
6. ዳወን ሲንድሮም ስላለበት/ባት ልጅዎ የቤተሰብ፣ ጎረቤት እና የማህበረሰቡን አመለካከት እንዴት ያዩታል?
7. ልጅዎን ሲያሳድጉ ያጋጠምዎት ማህበራዊ እና ሌሎች ችግሮች ምንድናቸው?
8. ከአከባቢው ማህበረሰብ ጋር ያለዎትን ግንኙነት እንዴት ይገልጹታል?
9. ከማህበረሰቡ ገር ተያይዞ የገጠመሽን ችግር እንዴት መቋቋም ቻልሽ/ቻልክ ?
10. ከዚህ በላይ ባለው ጥያቄ ያልተሸፈነ ነገር አለ እና የበለጠ ማብራራት የሚፈልጉት

APNNX: II

Key informant interview Guide

Part I. Background information of the organization

a) Location of the project: Sub City__________ Woreda _______ Telephone ___________
b) When was the organization established? ____________
c) Vision and mission of the project________________
d) Total number of the project beneficiaries: ______________________
e) What are the organization source of funding? ____________________
f) Date of employment in the organization _______________________
g) Your position or career in the project ________________________

Part II. Focus of service

a) What service does your organization provided?
b) What type of service does your organization provided to parents having a child with Down syndrome?
c) Is there any awareness training education about Down syndrome given to the family in your organization?
d) Does the organization provide financial support for the family?
e) How does the organization observe the attitude of community in such kind of intellectual disability?
f) Does the organization make any advocacy for the community to reduce stigma and discrimination?
g) What is the role of the organization in decreasing stigma and discrimination against parents raising a child with Down syndrome?
h) How does the organization involve in psychosocial support to parents having a child with Down syndrome?
i) Does the organization provide home based care to the children and family?
j) How social worker could assist them to address the challenges they face in parenting their children with Down syndrome?

APNNX III

Amharic version of key informant interview guide

ክፍል 1፡ የድርጅቱ የጀርባ መረጃ

1. የድርጅቱ ቦታ ________________ከ/ከተማ_________ ወረዳ_________ ስልክ ቁጥር_____
2. ድርጅቱ መቼ ነው የተቋቋመው____________________
3. የድርጅቱ ራዕይ እና ተልዕኮ ____________________________________
4. አጠቃላይ የፕሮጀክቱ ተጠቃሚዎች ብዛት__________________________
5. የድርጅቱ የገንዘብ ምንጮች ምንድን ናቸው? _____________________
6. ድርጅቱ ውስጥ የተቀጠርሽበት/ የተቀጠርክበት ቀን _________________
7. በድርጅቱ ውስጥ ያልዎት የስራ ድርሻ ____________________________

ክፍል 2፡ በአገልግሎቱ ላይ ያተኮሩ ጥያቄዎች

1. ድርጅቱ ምን አይነት አገልግሎቶችን ይሰጣል?
2. ድርጅቱ ዳወን ሲንድሮም ያለበት ልጅ ላላቸው ልጆች ድጋፍ ይሰጣል?
3. ድርጅታችሁ ለወላጆች ምን አይነት አገልግሎት ይሰጣል?
4. በድርጅታችሁ ውስጥ ስለ ዳወን ሲንድሮም የሚሰጥ የግንዛቤ ማስጨበጫ ትምህርት አለ?
5. ከድርጅቱ ለወላጆች የሚደረግ የገንዘብ ድጋፍ አለ?
6. ድርጅቱ ማህበረሰቡ ስለ አእምሮ እድገት ውስንነት ያለውን አመለካከት እንዴት ያየዋል?
7. ድርጅቱ በማህበረሰብ ውስጥ ያለውን መገለልና አድልዎን ለመቀነስ የሚደረግ የማስተማሪያ ፕሮግራም አለው?
8. ድርጅቱ ዳወን ሲንድሮም ያለበት ልጅ ላላቸው ወላጆች በሥነ ልቦና ማህበራዊ ድጋፍ ላይ የሚሳተፈው እንዴት ነው?
9. ድርጅቱ ለልጆች እና ለቤተሰብ ቤት ለቤት የሚሰጠው ግልጋሎት አለ?
10. የማህበራዊ ጉዳይ ሰራተኞች ልጆቻቸውነ በማሳደግ ረገድ የሚያጋጥሙዋቸውን ፈተዎች ለመፍታት እንዴት ይረዱአቸዋል?
11. የድርጅቱን አስተዋጾ እና ተግዳሮቶች እንዴት ያብራሩታል?

APNNX IV

Observation Checklist

1. What is the main challenge of the parents which continuously raised in their discussion?
2. How do they manage these challenges?
3. Adaption strategies mostly used by parents
4. The strong side of the parents
5. Parents satisfaction by the organization service
6. Area parent need a support