Reactions, Challenges and Coping Mechanisms of Mothers Raising Children With Autism Spectrum Disorder (ASD): The case of Addis Ababa City

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Abstract

Autism Spectrum Disorder is a complex neurological disorder which causes impairments in multiple areas of development including social interaction, communication, and behavior. There is clear evidence that parents of children with autism face many challenges in dealing with their children's difficult behaviors that can lead to negative psychological outcomes, including exhaustion, stress and depression. Moreover, it is evident that parents encounter social challenges such as problems on family relationship and lack of understanding attached to the disorder by society that lead to discrimination not only of the autistic child but also of the family as a whole. However, despite the many challenges parents of children with autism usually identify coping strategies that will work for them. This study therefore aims to explore the lived experiences of mothers raising children diagnosed with autism on the psychological and social challenges they faced as well as coping mechanisms they found effective in dealing with those challenges. A qualitative phenomenological research design guided the data collection and analysis which included six deep interviews that were recorded. The results that were conceptualized under the four research questions containing fourteen themes indicate that raising a child with autism is characterized by many psychological and social challenges such as mothers lack of information and support during the time of diagnosis, worry about child's future, stress from managing a child with autism, not having a time for oneself, effect on family, difficulty finding education and treatment for their children and lack of understanding followed by negative comments from the society.

Chapter One

Introduction

1.1. Background

Parenting starts when there is a plan for it because it can change how people define themselves and shift their priorities in fundamental ways. Thus, before their baby is born, many parents prepare themselves for making a lifelong commitment by putting a lot of expectation about the baby they are expecting. This expectation includes having a child who is completely healthy but according to American Psychiatric Association fact sheet (2014), about 1 in 68 children are diagnosed with autism spectrum disorder across the world.

Autism Spectrum Disorder (ASD) is an increasingly popular term that refers to a broad definition of autism including the classical form of the disorder as well as closely related disabilities that share many of the core characteristics (The Council for Exceptional Children, 1999). Therefore, the two terms which are autism spectrum disorder and autism will be used interchangeably in this thesis since the two words refer to the same developmental disorder.

American psychiatric association (2014) specified *"People with autism tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships and they may be overly dependent on routines, highly sensitive to changes, or intensely focused on inappropriate items."*

As Sonya (2006), indicated ASD comprises the third most common developmental disability in which males are three to four times more likely to be affected than females. In western countries the average age for an ASD diagnosis is between 4.5 to 5.5 years of age, with 51–91% of these children exhibiting traits prior to age 3 (National Autism Center, 2011 ; Tiffany, 2010).

However, late diagnosis continues to be observed in Africa (Bakare & Munir, 2011; Bello-Mojeed et al, 2011). According to Bakare et al. (2009); Bakare & Munir (2011); Bello-Mojeed et al (2011), the possible factors that are viewed as reasons for late identification and diagnosis of autism among African children include poor awareness about the problem, cultural beliefs, inadequate number of trained staffs, inadequate healthcare and intervention facilities.

In addition, to date, a representative community-based epidemiological study on prevalence, diagnosis, etiology and treatment of ASD among African children is not available (Mashudat et.al, 2013). Although, the American Psychiatric Association fact sheet (2014), indicated that about 1 in 68 children is diagnosed with autism across the world, in most African countries, it is difficult to estimate exactly the number of children with autism due to the tight statistical data available (Joachim and Robert, 2012).

However, prevalence of autism spectrum disorders among children with developmental disorders in Nigeria, prevalence of autism spectrum disorders had been noted to be 0.8% of the total population of children that attended clinics over a one year period (Bakare and Munir, 2011).

Similarly, the lack of scientific researches and documented data about autism made it impossible to find a statistical prevalence of the case in Ethiopia but in an article by Getnet (2013), by estimation it is believed that 0.70 % of the total population in Ethiopia lives with Autism and 75 % of those cases have learning disability accompanying there autistic case.

In western countries the community is more aware about autism because of increased media coverage and an expanding body of knowledge published in professional journals (Johnson and Myers, 2007). Relatively insufficient attention has been given to autism in sub-Saharan Africa. Although a few documented studies have examined the relationship between

autistic impairments and the stress on mothers, there is virtually very little on this subject in sub-Saharan Africa (Bello-Mojeed et.al, 2013).

It can be concluded from the articles the student researcher viewed that autism is the fastest growing diagnosed developmental disorder worldwide and there are sufficient researches done, intervention and educational institutions in the developed world that gives support to the parents of autistic children but less in Africa particularly in Ethiopia. Thus, this thesis focused on exploring coping mechanisms that mothers of autistic children use to cope up with the psychological and social challenges that autism entails.

From the researchers point of view studying mothers' experiences with the diagnostic process, the perceived impact of raising a child on the spectrum for themselves and their family, their experiences of accessing supports and services, their vision for the future of their children, as well as any advice they would give to other mothers of children with autism could be beneficial in acquiring tangible knowledge for participant parents, other parents who have the same experience and stakeholders that are directly working on the developmental disorder.

1.2. Statement of the Problem

Becoming a parent can be seen as both an opportunity and challenge. It can be an opportunity by providing goals to pursue that contributes to parents' understanding of purpose in life, satisfying human needs, infusing positive emotions into a parent's life and boosting a parent's identity with multiple social roles and enhanced life satisfaction (Nelson, Kushlev and Lyubomirsky, 2013). It can also be a challenge as a result of fatigue and being restless because of the many chores, frustration, financial strain, strained partner relationships and excessive worry about children's safety (Nelson, Kushlev and Lyubomirsky 2013).

Existing research has shown that the stress could be even more for parents of children with special needs. Having a child with developmental disability challenges parents by impairing their expectations for their children that can lead to fear for the future of their child and emotional distress in many domains of their lives (Gona, Mung'ala-Odera, Newton, and Hartley 2011).

Angold et al. (1998), also stated that parents of children with special needs undergo strain because of unusual demands that comes with the child with special needs, difficulty in social relationships and exhaustion from caring to the child, financial difficulties, guilt and parenting distress. However, these challenges depend on factors including parent demographic factors (e.g. age, educational status, economic status, gender), parent psychological factors(e.g. parenting style, social support) and child demographic factors (e.g. age, severity of the disorder) (Gona, Mung'ala-Odera, Newton, and Hartley, 2011).

This is also true for autism since one of such special needs that a child may be born with is ASD. Studies have shown that when a child is diagnosed with autism, parents are often at higher risk for many negative psychological outcomes. For instance, a study by Aadil et.al (2014), found that parents having children with ASD face many challenges as the disorder is associated with challenging anti-social behaviors, teaching their child to communicate, teaching basic life skills, guarding their child from danger, and preparing their child for adult life.

Furthermore, Richmond, Brian and Pena (2009), indicated that parents reported numerous types of child related stress (e.g., acceptability, hyperactivity), depression, anxiety, frustration, social isolation, and spousal relationship problems.

Especially mothers make the most intense adjustment to a child's developmental disability and they are at a higher risk of long term stress than fathers (Nisha and Susan, 2010). Mothers appear to be the most affected and to experience psychological distress (Aadil et.al , 2014)

because the mother tends to have the first role in caring of child with autism disorder and they endure greater psychological pressure than other family members in balancing children needs with their normal life (Hossein , Ayyub, Jalil and Nafiseh, 2013).

In most cases mothers become closer to the child with autism while father works harder to earn money consequently, the father becomes irritated at the demands of the mother to interact with a child and mothers become frustrated at the lack of involvement of their partners (Aadil et.al, 2014). Aadil et al (2014), also described this absence of informal and professional support, feelings of loss of personal control, and lack of awareness in society are some of the factors associated with mothers' stress in families of children with autism.

Supporting this, in a study by Kirsten (2008), participants described a lack of awareness of autism in society at large, which led them to believe that the majority of people do not understand the behavioral manifestations of autism that made them feel judged on how they manage their child's behavior.

Further, the social stigma attached to the disorder as the result of this lack of knowledge and awareness about autism is another challenge to mothers of an autistic child. Consistently, Pauline (2014), reported that mothers of children with autism reported that interacting with the outside world and extended family is difficult because of the stigma experienced due to public display of these behaviors.

Especially in less developed countries particularly in Africa societies lack awareness about autism and this lack of knowledge resulted many consequences. For instance, in a Zambian study by Joachim and Robert (2012), several parents reported that the burden of responsibility for their child on the spectrum was worsened by unsympathetic comments from the general public which shows that many people are not aware of the condition, hence stigmatizing both the

child and the parents. In another study from Uganda by Bwana and Kyohere (2001), caregivers of children with disabilities, who are mainly mothers or grandmothers, are subjected to stress in the form of physical conditions as a result of isolation from the society. Similarly, as stated in an article by Getnet (2013), more than 80 % autistic cases in Ethiopia face a lot of stigmas.

From the researcher's point of view, this lack of awareness and misperception of the developmental disorder may be the result of insufficient research done in Africa since many studies that have targeted mothers of children with Autistic Disorder are conducted in western or developed eastern countries. Supporting this, Bello-Mojeed et.al (2013), indicated autism spectrum disorder is a serious and disabling neuro-developmental disorder but relatively little attention has been given to its early identification, the pattern and impacts on the primary caregiver of children with autism in sub-Saharan Africa.

As indicated in the World Health Organization's world report of disability WHO (2011), one of the main obstacles that hinder the establishment of efficient support programs for parents of children with Autistic Disorder in the developing countries is the lack of studies that can inform about the impacts of raising children with autism on their parents and lack of adequate number of centers and trained staff.

Another factor that challenges African mothers is loss of adequate information and knowledge about autism which leads them to face extreme difficulties in dealing with the challenging behaviors. As Joachim and Robert (2012), indicated most parents in Zambia had no knowledge about ASD and felt that they were not fully empowered with information about autism by professionals before or after diagnosis. According to the report of J-CCARDD (2005), most mothers of autistic children in Ethiopia also lack information about the nature of the problem and its symptoms.

Lack of appropriate services and insufficient special education provision may be another challenge to mothers of children with autism in Africa. A study by Bello-Mojeed et.al (2013), revealed that caring for children with autism constitute a significant source of psychosocial burden of care on mothers due to the lack of educational institutions that provides intervention and appropriate education for their children.

In addition, Bwana and Kyohere (2001), indicated that caregivers of children with disabilities had insufficient time for other household chores and other social interactions as a result of being engaged in caring for their children fulltime because of the lack of educational services.

As the researcher observed this might also be true in Ethiopia. In our community usually mothers of children with developmental disabilities stay home to attend to the child because those children usually don't have access to early childhood centers. To make matters even worse, it might be hard to find a nanny willing to take care of such children.

To the knowledge of the student researcher, finding childcare services for a child with ASD can be challenging in our country because the overall situation of child care, educational and intervention services for those children in Ethiopia is far from satisfactory. In the education area the researcher could not find any specially designed curriculum, syllabus and modules that intend to meet the educational needs of children with autism spectrum disorder in the regular schools.

Supporting the student researcher's observation a paper prepared for the Education for All Global Monitoring Report for united nations educational, scientific and cultural organization by Lewis (2009), stated that even if Ethiopia have an estimated number of 1.7 to 3.4 million school-age children with special needs, less than 1% of children with special needs have access to

education in the country. Lewis (2009), also attributed that children with special needs do not go to school because teachers are not patient with them in the mainstream schools and fellow students do not understand their difficulties; while in the special school system there are too few schools, which are too far from home mostly confined to urban areas and have long waiting lists.

However, many parents cope successfully to the demands of raising a child with autism and have many positive outcomes from having a child with autism. For instance, according to a survey study of family resilience on parents of children with autism Bayat (2007), detailed that parents cope successfully to their child's autism and a number of these parents show resilience such as family connectedness and closeness and spiritual and personal growth.

Specifically mothers of children with autism manage and cope with the various forms of severe impairments present in their child's special needs and tolerate the psychological and social burden of their child's condition (Bello-Mojeedet.al, 2013). Supporting this, Matthew (2006), argued that most mothers begin by seeking formal social support in caring for the child with autism. Mothers also cope by creating positive meaning out of the situation, by focusing on personal growth and through religious means (Nisha and Susan, 2010).

Obviously, some manage to cope better than others, but little is known in our community about the strategies and techniques that they employ to a resemblance of normal family life. Therefore, From analyzing the studies and articles about the above mentioned challenges that parents specifically mothers of children with autism face and that those mothers can cope successfully to have as a settled and managed life as other mothers the student researcher got motivated to study these challenges and the coping mechanisms that are found to be effective by mothers having autistic children.

To the knowledge of the researcher in Ethiopia the psychological and social challenges of parents who have autistic children is less studied with primary intention of addressing those problems and finding solutions for better psychological and social adjustment of the autistic child and his/her parents. Therefore, the aim of this study is to examine the psychological and social challenges that mothers having autistic children face and identify the coping mechanisms implemented to cope with and overcome those challenges.

1.3. Objective

The general objective of this study is to investigate the experiences of mothers of children with autism spectrum disorder on the psychological and social challenges and the coping mechanisms they use to deal with those challenges.

1.4. Research Questions

(1) What were the major reactions and experiences of mothers during the time of their children's diagnosis?

(2) What are the particular psychological challenges faced by mothers raising a child diagnosed with autism?

(3) What are the specific social challenges faced by mothers raising a child diagnosed with autism?

(4) What are the coping strategies used by mothers of children with autism to deal with the often extreme psychological and social demands that autism entails?

1.5. Operational Definitions

Autism Spectrum Disorder (ASD) – a range of complex developmental problems manifested by either atypical behaviors in social impairments, communication difficulties, and restricted,

repetitive, and stereotyped patterns of behavior (as defined by professionals in the study site of this study which is Addisu Michael higher psychiatry clinic).

Psychological challenges – are difficulties people encounter that cause them unpleasant feelings such as unhappiness, fear, worry, anxiety, stress and hopelessness that can impact their activities of day-to-day living.

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

Coping mechanisms – refers to the use mechanisms of adjusting to environmental stresses and challenges without altering personal goals weather it is consciously or unconsciously.

1.6. Delimitation

The study was limited on mothers of children with autism spectrum disorder that diagnosed their children on autism spectrum disorder as the main source of information. In addition the study is limited on selecting samples from only one organization Addisu Michael higher psychiatric clinic that provides assessment, diagnosis, inpatient and outpatient medical (psychiatric) treatments and psychological therapies for many psychological and developmental disorders including autism spectrum disorder for the past twelve years. This is due to that the researcher only found this organization that is willing to provide the necessary support for the student researcher and that has professionals that diagnoses and levels the children whether they have autistic spectrum disorders or other developmental disorders by the criteria of American psychiatric association DSM-5 using verbal and nonverbal clinical tests.

1.7. Significance of the Study

Studying the challenges mothers' of children with autism spectrum disorders face and the coping mechanisms they used and are using to deal with those challenges is important to create

awareness and provide relevant and updated information on the issue to parents, professionals, centers that work on children with autism and the community at large. It gives additional insight to the autism centers so that they can employ various means and options to encourage parents and professionals to come together to work on the gaps and insufficiencies that the centers has.

The current study will obtain extensive and detailed information that is directly relevant to the participating parents and hopefully to other parents of children with autism by providing important insights into the emotions and thoughts inherent in these parents' experiences, which will inform current understanding of what it can mean for parents to live with an autistic child. It will also provide insight on what mechanisms are proved to be effective by previous studies to reduce the challenges and create a harmonious, coherent family lifestyle which is supportive for their children with autism. This study will also serve as a bench mark for interested researchers for further studies.

1.8. Limitations of the Study

There are a number of limitations in this study including difficulty to find more voluntary mothers' meeting the criteria of having a well-documented diagnosis of their children on autism even if autism is more prevalent in recent years with an increase in parents who are raising a child diagnosed with autism.

However, an in-depth phenomenological research design that can ethically be done with only six participants for this study allowed the researcher to gather valuable insight into the lived experiences of the participants through rich descriptive data that was gleaned from these participants.

Second, the majority of mothers in this study lived in Addis Ababa which is the capital city and therefore closer to the few services that are available in the country. It is possible that

mothers living in other cities and more rural areas where access to services such as schools for children with autism are almost none may have a very different experience when compared to the mothers in this study.

Another limitation of the study is the different types of autism spectrums that children of the mothers interviewed have can cause different levels of challenges in mothers since autism is such detailed and unique with so much variation in every individual on the spectrum. Therefore, it would be beneficial to expand the study to a larger population by addressing the unique characteristics of each child with autism through different challenges and burdens they caused on their mothers.

Chapter Two

Review of Related Literatures

2.1. Overview

The literature review provides a detailed account of the current information available on the diagnostic procedures for autism, and how parents responded to the diagnosis of their children from different studies across countries on the first section. After the diagnosis parents often seek to get information on the causes of their child's special needs, also they usually draw their own explanations on how their child is growing differently. Therefore, a review of the recent literatures on the causes of autism as well as parents specific perceptions on the causes of their child's developmental disability cross cultures will be demonstrated in the following section.

Autism can have a profound impact not only on the diagnosed child, but also on immediate and extended family members particularly mothers. Thus, this chapter further considered international, continental and local literatures about parents' experiences on the effect of autism on different aspects of their life and then the psychological and social challenges of mothers caring for a child with autism.

Over time, most parents may identify coping strategies that work for them and, in turn, they may adapt to the experience of having a child with autism. Thus, the coping strategies and resources a family more specifically mothers impacted by raising a child with autism used and are using to deal with the challenges and to what extent those strategies helped will be reviewed from several related studies. Finally, the theoretical framework which is Bronfenbrnner's Ecological theory will follow explaining how children with autism influence and are influenced by the institutions in their environments in different ecological levels including family, education, religious and other supporting settings.

Generally, the intent of the literature review is to provide background knowledge on the above mentioned aspects of autism so as to allow for deeper exploratory of the firsthand information by the researcher that provides educational material to the reader and to build a framework and foundation for the study which establish the gaps in the literature that the study is addressing.

2.2. Diagnosis of Autism Spectrum Disorder

Early diagnosis, Screening and evaluating are important for the child and the parents to ensure that these children access the services and supports they need (Susan, 2011; Autism and Developmental Disabilities Monitoring Network (ADDM), 2014). There for, the diagnostic criteria for autism and what they mean in terms of everyday Symptom appearance will now be reviewed in detail.

In western countries the average age for an ASD diagnosis is between 4.5 to 5.5 years of age, with 51–91 percent of these children exhibiting traits prior to age 3 (National Autism Center, 2011 ; Tiffany, 2010). However, late diagnosis continues to be observed in Africa (Bakare & Munir, 2011; Bello-Mojeed et al, 2011). The factors that are viewed as reasons for late identification and diagnosis of ASD among African children include poor awareness about ASD, different cultural beliefs, inadequate number of trained staffs, inadequate healthcare and intervention facilities (Bakare et al, 2009; Bakare & Munir, 2011; Bello-Mojeed et al, 2011).

As listed in Scottish Intercollegiate Guidelines Network SIGN (2007), a complete evaluation and diagnosis of ASD includes developmental history, observations, direct interaction, and parent interview preferably over more than one occasion, and in more than one setting. Professionals usually diagnose ASD using criteria set forth by the Diagnostic and Statistical Manual-IV-TR (DSM-IVTR, 2013) worldwide.

According to the American Psychiatric Association DSM-5 (2013) to be diagnosed on autism a child should show the following criteria clearly atypical and they must be presented across multiple contexts:-

A1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction.

A2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.

A3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people.

B1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypes, echolalia, repetitive use of objects, or idiosyncratic phrases).

B2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior or excessive resistance to change such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes.

B3. Highly restricted, fixated interests those are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed interests).

B4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

C. Symptoms must be present in early childhood (but May not become fully manifest until social demands exceed limited capacities)

D. Symptoms must together limit and impair everyday functioning. (American Psychiatric Association (DSM-5), 2013)

2.2.1. Parents' Experiences on the Diagnosis of their Children on Autism Spectrum Disorder Across Cultures

Just as each child with autism is unique, each parent's response to the ASD diagnosis is also unique. Several studies have focused specifically on how parents react to initially hearing the news that their child has autism because parents' experiences at the time of the diagnosis predict future family adaptation to the spectrum, parental stress, and parents' information needs (Murphy and Tierney, 2007).

In a survey based study conducted in the United States by Bayat (2007), with 175 parents of children with ASD the participants reported initially experiencing depression when they found their child is diagnosed with autism. Similarly, in Altiere's study (2006), many of American parents experienced despair, sadness, denial, confusion, and anger when they discovered that their child had autism. In this study the mothers were more likely to quickly overcome these feelings and organize their resources to find help for their child than the fathers.

Likewise in Scotland, a phenomenological research by Kristen (2008), revealed that some parents found receiving a diagnosis as a significant and stressful life event. To the parents in this

study, the diagnosis meant a sudden loss of the potential for their child to achieve all the things they take for granted, such as living independently, getting married and having children. In addition, despite the fact that diagnosis brought answers to explain why things happened, most of these participants reported it brought more questions and confusion. Another study by Angela (2013), on 13 Jamaican mothers raising children with autism mothers also demonstrated a range of emotions immediately following the diagnosis including despair, sadness, or being overwhelmed at the news.

Further a study from an Asian country South Korea reveled that autism is highly stigmatized culturally and therefore not commonly diagnosed as a result of mistrust of the medical community and parents' rejection of expertise in favor of their own views (Grinker et.al, 2013). However, McCabe (2008), from another Asian country China found feelings of shock, devastation, and lack of information on the parents of children with autism related to having a child diagnosed on the spectrum.

Correspondingly in Africa Lara (2007), in her study that conducted a needs assessment of parents of children with autism in South Africa found that during the period of the diagnosis the contacts with the health professionals were experienced as frustrating for the parents and receiving the diagnosis for their children were challenging and an emotional experience.

Similarly, in a Zambian phenomenological study that investigated parents' lived experiences in 17 educated and urban parents of children with ASD by Joachim and Robert, (2012), all the parents confirmed that a diagnosis was a much desired, time-consuming and difficult process. The reaction of parents to the diagnosis ranged from relief to confusion and fear for the future of the child. However, Parents who had more than one child with a disability and

those who had prior knowledge of ASD reported a milder reaction than those whose child was the first born.

To summarize, the recent literatures reviewed by the student researcher harmoniously shows that diagnosis of a child with autism is a much desired process by parents to know what exactly differs the development of their child from other children. However, late appearance to health care institutions and late diagnosis is reported by studies from Africa than western studies. These literatures also indicated that most parents felt the diagnosis process as frustrating and shocking which leads them to want being provided with more detailed information about autism than they had provided with during the time of diagnosis to take further actions.

2.3. Causes of Autism

From the several controversies regarding the cause of autism it is known that there are likely many causes for multiple types of ASD. Finding the cause has been intimidating because of genetic complexity and phenotypic variation in the developmental disorder which makes it a complex disorder that involves multiple genes (Johnson and Myers, 2007). This section of the literature will review the possible causes of autism from different findings and parents beliefs about the causes of their child's neurological disorder across the globe.

Autism is multi-factorial disorder in which many factors come into play when determining the cause including complex genetic interactions, nutritional deficiencies or overloads, pre- and post-natal exposure to chemicals or viruses and dysfunctional immune systems (Sonya, 2006).

According to Centers for Disease Control and Prevention CDC (2009), and Volkmar (2009), most scientists agree that genes are one of the risk factors that can make a person more likely to develop an ASD. For example, two identical twins are likely to have autism than two fraternal twins (European commission health and consumer protection directorate (ECHCPD),

2005). The first study that looked at twins and ASD was carried out in 1977 by Folstein and Rutter in a study that included 21 pairs of twin boys, 11 identical and 10 fraternal and found concordance for autism in four of the 11 identical sets of twins and none in the fraternal twins.

Supporting this Sonya (2006), also demonstrates that studies involving families in which more than one member is affected with ASD have provided information to conclude that: *"the identical twin of an individual with ASD has better than 90% chance of also being affected; a fraternal twin or sibling of an affected individual has 15% chance of having ASD; and an ASD parent has a 10% chance that his or her offspring will also have ASD".*

Further, since it was discovered that autism manifests itself before the age of 3 years, environmental risk factors from conception to immediately after birth have been investigated. However, no single environmental factor is exhibited as a cause of autism in any study the student researcher of this thesis reviewed but many environmental risk factors have been suggested based on data from human studies and animal research and it is clear that many more are still under investigation. Thus, the following paragraphs consist some of the known environmental risk factors.

Infections specially maternal and early infant infections and vaccinations are among the categories of possible risk factors for autism that have gained the most attention (Dietert, Dietert, and Dewitt2010). There have been reports associating autism with infections either before or at the time of birth or shortly thereafter which include congenital rubella, cytomegalo virus, herpes simplex, and human immunodeficiency virus (HIV) (volkmar, 2009).

Consistently, Sonya (2006), indicated that exposure to cytomegalo virus and rubella during early pregnancy is thought to increase the risk of having an autistic child as related to the observation that many autistic individuals have impaired immune systems and decreased number

of helper T-cells. This is in line with Philip (2010), who argued that autism occurs in combination with other irregularities typical of the congenital rubella syndrome, including eye defects, deafness, mental retardation and cardiac malformations.

Further, Hideo et.al, (2012), stated Vaccinations for measles, mumps, rubella (MMR), pertussis, and tetanus (DPT) are also the causes of the recent increase in morbidity rate of autism. From these environmental factors, MMR vaccine has drawn attention. However, studies in autism and MMR immunization in United States have demonstrated no correlation between increased prevalence rates of autism and increased rates of immunization for MMR (Barrett, 2004) and this association between autism and vaccinations is controversial because the link between ASD and childhood vaccinations is unclear (Tiffany, 2010).

Another environmental cause for autism to be considered is prenatal exposure to teratogens (an environmental agent that can cause abnormalities in a developing fetus) (Fombonne, 2006). The critical period for exposure to teratogens shown to increase the risk of autism is early in the first trimester of pregnancy and Thalidomide (THAL) and valproic acid (VPA) have been confirmed as teratogen drugs linked to the risk of autism in many studies (Hideo et.al, 2012).

Studies reveal exposure to pharmacological agents particularly during pregnancy represents a highly related environmental concern to the risk of autism as another teratogen. For instance, as Dietert, Dietert, and Dewitt (2010), stated the changes in availability and use of certain prescribed drugs and non- prescribed drugs such as thalidomide and VPA are among the best examples to the growing rate of prevalence of autism.

Supporting this Wier et al. (2006), describes a study of Swedish patients where prenatal exposure to a teratogen occurred in a greater proportion of autism. They suggest that the first trimester injury may impair brain development, which potentially leads to autism.

Other several environmental agents were identified as strong contributors to learning and developmental disabilities in humans. As indicated in an article by Philip (2010), studies of lead and methyl and mercury has documented that toxic chemicals can damage the developing human brain to produce a spectrum of neuro-developmental disorders. Phillip further argued Children today are at risk of exposure to synthetic chemicals termed high production volume (HPV) chemicals which are found in consumer goods, cosmetics, medications, motor fuels and building materials and they are common in waste sites.

2.3.1. Parents' Perceptions About Causes of Their Child's Developmental Disability Cross Cultures

According to the literatures reviewed by the researcher of this thesis parents' underlined view for the causes of their children's neurological disability varies widely through cultures. For instance as indicated in a study by Russell & Norwich (2011), from the United Kingdom, parents perceptions to the causes of their child's ASD symptoms were the result of biological factors and neurological differences.

Correspondently, from a study by Altiere (2006), in United States the majority of parents agreed with the scientific findings that to this date no one has discovered an exact cause of autism however, Measles, Mumps, and Rubella (MMR) vaccination, genetic and/or environmental cause was the most frequent cause listed by parents.

As well, a study by Shaked & Bilu (2006), in Israel which focused specifically on beliefs surrounding etiology of ASD symptoms found majority of parents reporting physiological causes including labor complications, problematic infant immunization, genetic inheritance, viral infection during pregnancy, serious disease in the first year of life, head trauma and organic defect in the brain as causes for their children's developmental disability.

In a Jamaican study by Angela (2013), most mothers believed that they were fated by God to have a special needs child and some thought there was a genetic risk that had led to their child's symptoms. Similarly, as the primary caregivers, mothers in South Korea bear their child's autism as everything from the mother's prenatal mood to post-natal diet (Grinker et.al, 2013).

However, in most African studies ASD is often viewed as a result of some misfortunes or wrongdoings by the parents or the ancestors of the autism child including witchcraft and evil spirits (Mashudat et.al 2013). For instance, as demonstrated in Bakare et al. (2009), participants from Nigeria often blames diseases like ASD on witchcraft spirits, hereditary causes or just simply bad parenting and views mothers as cold and uncomfortable to their children.

Similarly in a dissertation by Anthony (2009), which provided a look at the understanding of autism in Ghana, parents especially mothers, were to blame for their child's symptoms either by not providing quality prenatal care, a failed abortion attempt involving ingestion of tonics and experiencing some illness or accident during the course of their pregnancy as the cause for ASD.

As well, from Joachim and Robert's phenomenological study (2012), in Zambia several families reported that the cause of ASD was witchcraft and/or noncompliance to customs and traditional norms in marriage. Joachim and Robert further stated that such thought leads to family conflicts on gender roles, marital conflicts, poor parental care and denial of the child's condition by parents particularly the father mainly if the child with ASD is a first born son who traditionally is treasured.

Generally, reviewed articles regarding to the cause of autism presents controversial causes which include various genetic and biological cases as well as environmental ones. From these complex genetic interactions, nutritional deficiencies, pre- and post-natal exposure to chemicals, viruses and/or teratogens are found to be common explanations for the causes of autism.

However, parents' explanation about the cause of their children's developmental disability differs across studies from different countries. Parents from well developed country raise more logical and near to scientific explanations where as parents from less developed and developing countries specifically from Africa raise more cultural and non-scientific explanations.

2.4. Parents' Experiences of Raising a Child with Autism

In the child's early years, after parents feel something is different about their child, they often experience a stressful period as their child's problems grow more noticeable and struggle to obtain an accurate diagnosis for their child (Gray, 2002). After wards families raising children with autism may be affected negatively when receiving the child's diagnosis because many children with autism are born without indication of behavioral, physical, or intellectual abnormalities (Tina et.al, 2004).

Moreover most families with an autistic child know little about autism or its implications (Paul, 2001) and this limited knowledge of autism by parents led to initial reactions of denial, fear, and shock during and after diagnosis (Lindsey and Roberta, 2013). These parents are generally left in shock and disbelief after diagnosis not knowing what course of action to take to help their autistic child and their families, including the siblings of the autistic child (Paul, 2001; Hossein, Ayyub, Jalil, Nafiseh, 2013). Thus, upon receiving the diagnosis, many parents reported that they wished they had received greater information surrounding resources, treatment, and prognosis for their child (Lindsey and Roberta, 2013).

Similarly, findings from Africa such as Joachim and Robert's (2012), Anthony (2009), and Lara (2007), also indicate that African parents experience challenges ranging from frustration, pain, confusion and doubt in the diagnostic period as a result of limited knowledge about autism. Most parents in these study appealed they had no knowledge about ASD which led them to poor

parenting of the child, parental stress, emotional and psychological distress, strain on the marital relationship and strain on relationships within the family.

Further, not only the parents lack of sufficient information about their children's autism but the lack of knowledge about autism by community at large is also challenging for parents. For instance, in a study by Lori (2008), participants reported that taking a child with autism out as a source of stress for parents because people may stare, make negative comments or misunderstand behaviors that may occur due to lack of knowledge about autism.

In line with this a qualitative research by Kristen (2008), purported that participants reported a feeling of being negatively evaluated by people around them and strangers are much quicker to judge as a result of general lack of awareness of autism in society at large, which led threat on their self-esteem.

In Africa, Mashudat et.al (2013), indicated that a child with neuro-developmental disorders is seen as a mark of shame on the family by the society due to misunderstanding of the etiology of different developmental disorders. Therefore, individuals with ASD and their families are often faced with negative attitude, avoidance, rejection, as well as negative and offensive comments which lead families to hide the affected child from the society (Mashudat et.al, 2013).

Similarly, the findings of many studies in Nigeria show a low level of knowledge and awareness about autism spectrum disorders by the society (Bakare et al, 2009). African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN) (2007), Nigeria chapter, in a World Bank sponsored program carried out a survey to determine the level of knowledge and awareness of health care workers and the general public in Enugu, south-eastern Nigeria about autism spectrum disorders and found that there is very low level of knowledge and awareness about autism spectrum disorders among the general population.

Similarly several parents from Zambia also reported that the burden of responsibility for their ASD child was worsened by unsympathetic comments from the general public which shows that many people in Zambian society are still not aware of the ASD condition, hence stigmatizing both the child and the parents (Joachim and Robert, 2012). Anthony (2009), also outlines pervasive stigmatization and isolation surrounding having a child on the spectrum in Ghana due to insufficient knowledge about developmental disorders.

The limited literature that the student researcher found also indicates that there is lack of awareness in Ethiopian society. For example, as stated in a report by J-CCARDD (2005), many children with autism in Ethiopia are neglected because some children with autism look normal physically; people often mistakenly imagine they are simply disruptive or poorly behaved. Likewise, Getnet (2013), indicated that Autistic cases in Ethiopia face a lot of stigma and more than 80 % of these individuals are isolated to control their unusual behavior.

With regard to how this lack of knowledge and stigma impacts treatment and education, many families report difficulty with accessing inclusive education for their child. Many parents of children with this disorder find it difficult to attain educational provision or help with their children compared to those who have children with other disabilities (Tiffany, 2010). For instance, parents from USA in a study by Altiere (2009), reported that they had spent extensive time trying to find services for their child with autism which become frustrating, stressful, and discouraging to a family.

Supporting this, Susan (2011), in her review of literatures on parental grief, coping Strategies, and challenges when a child has autism spectrum disorder in USA claimed parents, particularly mothers, may be unable to return to work because childcare centers refuse to take the child. Susan further stated they will want to meet the child and observe him in the day care

setting before agreeing to allow the child to attend because many childcare facilities are privately owned and locating a babysitter willing to stay with the child can be difficult.

Correspondently with Susan, McCabe (2007), studied the experiences of families of children diagnosed with an ASD living in China in accessing services and supports for their child and found that even if parents have a desire to have their children go to school, they face rejection from general education schools and it was also noted that special education schools in most areas are limited in China.

Further, Angela (2013), illustrated that many children diagnosed with ASDs living in Jamaica have very limited access to educational settings. Most mothers from her study reported difficulties finding respite care, appropriate educational settings for their child and that most educators and schools in Jamaica are extremely under-prepared for supporting the needs of children with ASD and the relatively high costs of educating a child on the spectrum for families.

Compared to the western countries with trained professionals, better access to child care facilities and available intervention services, African children have limited access to the few available services (Bakare & Munir, 2011; Bello-Mojeed et al, 2011). The non-availability of child health care and education services and the poor access to the few available ones which are concentrated in the urban areas makes it difficult for families of African children with ASD to get them necessary intervention and education programs (Mashudat et.al, 2013).

For instance, Joachim and Robert (2012), point out that all participants noted that services provided to their children were not sufficient or adequate and that there were no preschools in Zambia exclusively for children with ASD and these children are generally avoided by mainstream school authorities. Similarly, in Ethiopia there is only one autistic center operating in Addis Ababa called Nia foundation, Joy autism center since 2002 until recently, giving a

special teaching for autistic Children while still there are a lot of these children looking for special education (Getnet, 2013).

Further Lewis (2009), in his paper prepared for the Education for All Global Monitoring Report for united nations educational, scientific and cultural organization stated that even if Ethiopia have an estimated number of 1.7 to 3.4 million school-age children with special needs, less than 1% of children with special needs have access to education in the country.

Lewis (2009), also attributed that disabled children do not go to school because teachers are not patient with them in the mainstream schools and fellow students do not understand their difficulties; while in the special school system there are too few schools, which are too far from home mostly confined to urban areas and have long waiting lists.

The above discussed social challenges including lack of knowledge about many features of autism by parents and the society at large, the insufficient medical and educational services in many countries and the behavioral existences of the neuro-developmental disorder itself lead parents of children with autism to negative psychological influences like stress and anxiety.

For instance, a research by Kristen (2008), in Scotland using phenomenological research design illustrated that the very nature of the symptoms seen in autism and the behavioral manifestations in children with autism lead parents to face many psychological challenges as an individual and to the wider family and its context. Moreover, parents of Autistic children are particularly vulnerable to stress and the levels of distress are higher in parents of severely disabled children because it is characterized by problems of social interaction, such as forming attachments and showing affection, mothers of children with autism are often denied some of the fundamental rewards of parenthood (Aadil et.al, 2014).

Supporting this, Krausz and Meszaros (2005), found mothers were greatly affected when children appear to have no emotional attachment, recognition or affection because mothers are often responsible for and highly involved in the daily care of their child.

Tiffany (2010), also illustrated that since children with autism do not typically express interest in sharing events or object with other people it can be stressing for mothers related to the concept of a child's attachment to the parent. Thus, any parent would have a higher level of stress when dealing with a child that requires more than the usual amount of attention and there can be a continual conflict of emotions. Parents showed a strong sense of having to find a balance between different extremes of emotion that may occur in response to specific events or aspects of their experiences like feelings of guilt, feelings of embracement, anxiety about whether their child was socially accepted (Kristen, 2008).

Consistently, in Gray's (2002), study parents reported their child's disability caused considerable upset. In particular, over half of the parents reported significant degrees of anxiety and depression and approximately a third of these were receiving psychotherapy or medication to help them cope and the parents who were the most distressed were those whose children were aggressive and/or severely obsessive. Similarly, the findings from Latafa (2014), indicate that Jordanian parents of children with Autistic Disorder suffer significant impairments in their psychological health which is negatively affecting their sense of parenting competence.

Further, the future of their child is another source of stress for parents. The failure of children to recover, plus their increasing age, has meant that their future residential location would be the concerns of their parents (Gray, 2002).

Equally, In Bayat's (2007), survey with 175 parents of children to examine the evidence of resilience in families of children with autism parents reported worrying about their child's future

as one challenge. Many parents worried about the child's level of independence and their ability to maintain relationships as well as what would happen to their child if they themselves became ill and could no longer take care of them (Murphy and Tierney, 2007; Kristen, 2008).

Finally, important sources for parental psychological challenges in families of children with autism include Stress from the difficulties of communication and behavior management arising directly from the child's condition, feelings of loss of personal control, absence of spousal support, informal and professional support which leads family members of children with autism to experience negative psychological and social effects including higher risk for depression, social isolation and marital discord (Aadil et.al, 2014; Mancil, Boyd and Bedesem, 2009; Joachim and Robert, 2012).

To conclude it is clear from the literatures reviewed above that parenting a child with autism is complex, characterized by grief and stress certainly in the early years and that raising a child with Autism can have a profound impact not only on the diagnosed child, but also on immediate family members specially parents, as well as on other systems external to the family, such as relationships with friends, colleagues at work, educational and support organizations.

As most of the literatures similarly suggest that there are many different contributing factors that may make parents' life more challenging due to their child's diagnosis of ASD including being unaware of the way they care for their children and little awareness about autism, worrying over the future of their child, marital stress, career problems, stigma from the society due to little knowledge about the developmental disorder, difficulty finding educational service for the child which will lead parents to experience negative emotions and psychological distresses in their daily lives.

2.4.1. Experiences of Ethiopian Parents' Raising a Child with Autism

It appears that the challenges families face in connection to developmental disabilities of children are more serious and complicated in the developing countries (Amakelew, Daniel and Fasikawit, 2000). People with special needs in developing countries have encountered many problems as governments of many of those countries had never committed themselves to providing various services for these large groups of citizens (Getnet, 2013).

The history of people with special needs in Ethiopia is not different from other developing countries. Special needs children in Ethiopia are among the most psychologically, socially, economically and politically disadvantaged social groups (Weldeab, 2006). In other words, to be special needs usually means to be discriminated against as well as suffering social isolation and physical restrictions (Letekidan, 2003).

Persons with disability do not have access to rehabilitative services, simply because the in availability of such service and due to the low level of attention given to developmentally disabled groups by past regimes and the present government. As a result parents and relatives of disabled were and are still the crucial actors in the provision of care and education for the majority of disabled children and youth (Meron, 2006)

In this part of the world' families that have children with disabilities suffer the problem more than their partners in the developed countries. Ignorance and inadequate schooling, extreme poverty and lack of welfare support, discord between family members and subsequent stress and/or separation among family members, unsafe physical grounds together with hostile or segregating neighbors aggravate the problem of mothers raising children with autism in Ethiopia (Amakelew, Daniel and Fasikawit, 2000).

For instance, a study by Aynalem, (2014) indicates that the impact of autism on Ethiopian mothers is expressively visible on their daily routines and life experiences and they do not feel at ease to talk about their children openly instead they feel guilty and are ashamed of their autistic children due to the pressure and misunderstanding of the society. As forwarded by participants in this study social life and participation in social events was limited as a result of raising their children with autism due to Preference to isolate one self and fear of taking child in public as a result of the low level of probability to get acceptance from the society.

Hence, thousands of children with autism are confined to their homes with no access to education or rehabilitation because some children with autism look normal physically; people often mistakenly imagine they are simply unruly or poorly behaved (Tirrussew, 2005). Because of the general lack of awareness, families and children with autism are often blamed for their actions and the disorder is sometimes seen as punishment for some spiritual wrong doing; in fact, with few Ethiopians even aware of autism's existence, more often than not the symptoms of the disorder are misrecognized and misunderstood, with tragic consequences (Letekidan, 2003).

To support this, Chernet and Opdal, (2007) described throughout Ethiopia, having an developmental disability is regarded as a source of shame and misconceptions and unfavorable attitudes towards special needs persons that result in continued stigmatization which in turn led those children to be hidden at home and kept away from schools and other intervention programs.

This level of social standing of special needs people is derived from how developmental disability is perceived in society (Abreham, 1998; Tirrussew, 2005; Weldeab, 2006, 1999; Weldeab & Endrerud, 2004). Consistently, Weldeab (2000) found that "*labeling persons after their impairment is still common in most parts of Ethiopia. … . In most places, people use such*

terms as an insult which really have psychological impact on persons having those impairments and their families". Getnet, (2001) also noted the problem lies in defining developmental disability since definitions of developmental disabilities has been the medical model it is one of the dominant influences in shaping both professional and common sense which resulted in a range of offensive responses by other people.

Moreover, the majority of the public including many professionals in the medical, educational and vocational fields are still unaware of how autism affects people and to effectively work with individuals with autism. As a result, children with autism have been deprived of the opportunities to gain or improve their academic, social and communication skills (Report of Joy Center for Children with Autism and Related Developmental Disorders [J-CCARDD], 2005).

As is the case in many developing countries, families in Ethiopia comprise the largest group of caregivers for children with disabilities. This is due to the fact that there is a lack of residential services and the vast majority of the children live with their families (Chernet and Opdal, 2007).

In a country like Ethiopia where developmental or mental impairments are considered as things related with curse or some sort of bad omen, opportunities to make life better or improve the situation of people with the problem is unsatisfactory(Letekidan, 2003).

According to the "Needs Assessment Report "conducted by Handicap National, (2012), fewer than 3% of children with special needs in Ethiopia have access to primary education, and access to schooling decreases rapidly as children move up the education ladder. Handicap International carried out a survey in the regions of Dire Dawa, Harar and Jijiga to try and assess the causes of children with disabilities dropping out of education. Families were asked to identify

reasons for children failing to attend school that fell into two broad categories: ’family-level’ or ‘school-level‘ causes. Most families and children reported that family issues – often related to work or caring responsibilities – are the main cause. When it comes school-level issues, “long distance to school” is the number one cause of drop-out.

As the report of Handicap National, (2012) further indicates in one of the Woredas in Addis Ababa it was reported that some parents are not willing to send their children to school or to play for fear of being endangered, hurt and segregated. Generally speaking, these parents face challenges in rearing children with developmental disability and they may not send the children to school because of a number of reasons, i.e. the education of the child with special needs may not be the priority for the parents'; inability to cover school expenses; lack of awareness of parents whether their child can be schooled or not; feelings of parents that the child may not receive the necessary support; fear of shame and guilt, etc.

Similarly Department for international development (DFID, 2010) Perceived barriers to educating children with special needs in Ethiopia may be physical, social or financial which includes discriminatory policy that actually segregates children with developmental disabilities, even if reasonable policy is in place not implemented, poor resource allocations to education for the developmentally disabled , limited training of teachers in working with children with disabilities and no incentives for teachers to do so, Social stigma and negative parental attitudes to developmental disability like autism which may arise out of religious and cultural beliefs, parental resistance to inclusive education for special groups , Low school budgets resulting in a lack of appropriate facilities.

Backward these societal attitudes and challenges perpetuate to influence parents of children with special needs psychologically which affects their life style and life chances (Getnet, 2001). The psychological and emotional stress by parents of children with the problem is immense since most parents of children with autism do not have information and knowledge about the symptoms of autism (Letekidan, 2003).

Some local researches show that most serious and probably most common problems parents of children with autism face in countries like Ethiopia relates to access to professional information and services. Most parents have no accurate and up to date information about their children's developmental disorder because the service system is often limited and fragmented that it is highly unlikely that there will be any single source of information that can tell parents of autistic children all they need to know at any point along the way (Amakelew, Daniel and Fasikawit, 2000)

As Aynalem, (2014) indicated Most of the families in her study are not aware of autism before the diagnosis process. The diagnosis process was also reported to be tiresome and long as most professionals in the medical setting were not aware of autism with a limited provision of psycho social support which risked these families to experience stress, shock, and anxiety.

As a result of this lack of knowledge by parents' studies like Amakelew, Daniel and Fasikawit, (2000) reveal that Ethiopian parents feel insecure and guilt-ridden because of imagined responsibility for the child's condition. They do some sort of searching for shortcomings of their own which might have caused autism in their children which made them feel ashamed of their children's backwardness and often try to hide them from friends and neighbors.

Through time and after getting more knowledge and experiences with their children's disabilities, parents face another psychological problem. They feel guilt that will never disappear but stay on part of the parent's emotional life of not recognizing the problem with the children in time (Getnet 2013).

Due to lack of awareness, the parents may demand behavior and intellectual achievement beyond the child's abilities in turn they feel ashamed of the mistake done in pushing the children beyond their capacity and losing patience with them (Amakelew, Daniel and Fasikawit , 2000). Similarly Meron, (2006) described that most mothers in Ethiopia suffer from life time regrets over the disparity of heart breaking reality that their children would have the problem for life that magnifies other existing problems, creates new area of conflict and feeling of hopelessness.

Furthermore, with little explanation for their children's behavior, and few sources of assistance, mothers of children with autism in Ethiopia carry an incredible burden. They remain without any aid, left alone to futilely plead for help, they must stay home to manage their children, they are unable to work because their children are often not allowed to attend regular schools for children their age (Aynalem, 2014). Aynalem also indicated that these mothers cannot even leave their children with relatives or neighbors; because their child's uncontrolled behaviors are misunderstood; recognized as the expression of poor parenting, or as punishment for sin.

Consequently, stress and anxiety are the common psychological challenges to these mothers raising a child diagnosed with autism 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 (Meron, 2006).

Therefore, it is extremely important to encourage good parenting by easing stress, providing up to date information and offering material or financial support to these families so that their children with autism can acquire self-care skills and have access to different public services (Getnet, 2013).

Since the perspectives of different dimensions of challenges and coping mechanism of families living with a child diagnosed with developmental disorders especially autism is less studied in Ethiopia the extensive challenge mothers face as a result of caring a child with autism and coping mechanisms employed will require a study to reveal the extent of challenge and to understand the appropriate psychosocial support needed for the family (Aynalem, 2014).

This is due to that success of educational and other intervention programs depends to a great extent on the current experiences and fulfillment of the needs of service providers themselves and especially the parents of children with special needs (Chernet and Opdal, 2007). Weldeab, (2006) supports this describing that in the absence of sufficient information about the practical experiences (challenges, barriers and facilitators) of parents and their specific needs, it would be impossible for any service providing programs to be effective.

First and for most, parenting is a skill that needs to be learned formally and informally through various means. As Amakelew, Daniel and Fasikawit, (2000) indicates in Ethiopia young mothers often pick up the parenting skills from their home environment specially from their parents, gran mothers, elder sisters, etc. but The challenges of parenting children with developmental disabilities require certain other skills which parents should receive from all corners to counter and cope with the negative community attitudes and traditional beliefs towards disability. Therefore, Special support and encouragement is essential for the parents to counter the social isolation of the child with disability in the community he/she is living and

Offering the necessary advises can equip parents with better skills to identify and intervene their psychological challenges early (Amakelew, Daniel and Fasikawit , 2000).

However, Chernet and Opdal, (2007) designated that the parents interviewed in their study as a whole, had limited coping resources and functioning. While other researchers like Bailey & Smith, (2000) and Moor & Moor, (2003) have found that coping resources and functioning are mediated by protective factors in the ecological systems within which parents interact. Some of these protective factors include a supportive social network, sufficient emotional support from friends and others, favorable attitude to and perceptions of disability in the larger society.

Chernet and Opdal, (2007) applied Bronfenbrnner's ecological model to the social system of Ethiopian society and noted that the traditions of Ethiopian society can become agents of change by using strategies such as organizing parent meetings, seminars, workshops, conferences as well as spreading information through leaflets and school media.

By working within the cultural traditional institutions of Ethiopia [e.g., "*coffee mornings*"] and Utilizing traditional social institutions like "*idir", "equb", "senbet", "mahber", "*as well as parents' perspectives as well as the attitudes of the larger society can be changed from the stigmatized negative stereotypes that seem to pervade the society's reference to and treatment of children with cognitive disabilities towards a more strengths-based perspective. (Chernet and Opdal, 2007)

For example, *idir* is a form of traditional social institution that is established by the mutual agreement of community members in order to collaborate with each other whenever any member or their family members face adverse situations. In these families' lived experiences, there had been no such collaboration to help them cope with raising their autistic child, clearly an

adverse situation. Nonetheless, *idir* may be the best tradition when it comes to changing the society's attitude as it usually brings together large groups of people from different religions and cultures (Chernet and Opdal, 2007).

Similarly, the tradition of *coffee mornings* involves the ritual ceremony where young girls of a family who are taught how to make and serve the 'first cup,' then the 'second cup,' and so on. Thus, *coffee mornings* are situations where parents (neighbors) meet and discuss social issues while drinking their coffee. In many cases, the main thing is not the coffee but the meeting itself because they (especially mothers) discuss different issues and find solutions for their problems. Therefore, service providers such as social workers and psychologists could come and join these neighborhood meetings to find normalized situations to explain about autism, treatment, expectations, and so on.

They could host coffee mornings themselves, thus facilitating social interaction amongst a group of community people on behalf of the parents. They could organize neighborhood study groups for people who would learn about special needs issues and then go out to teach others. In this way, members of the community or neighborhood (i.e., the mesosystem) can be led to change their attitudes towards developmental disability and towards their neighbors whose children have a developmental disability. When the society changes its attitudes, then the parents' challenges would be minimized.

This implies that, especially in Ethiopian communities where people from a variety of cultures and beliefs are living together, without the prior understanding of how the communities and families perceive those with special needs, it is very unlikely that any intervention programs can become effective without some adaptation to the traditional customs. Professionals and the

traditional mediators of the society (e.g., the priests and ministers, the psychologists and teachers) must understand the parents' situation and attitudes, their values and life situations.

To summarize, as can be gleaned from the above literatures the "voices" of families in Ethiopia, speak loudly, clearly, and, often, plaintively, about their many psychological and social challenges and their need for education about the nature of autism and about their desire to find better ways to improve the lives of their children. Therefore, Professionals should ally themselves with the parents to form partnerships, provide information and new understanding to them especially if collaboratively developed by the traditional institutions as represented by church officials, the programs could be valuable methods to help parents perceive their children as gifts from God.

2.5. Psychological and Social Challenges of Mothers of Children With Autism

Findings suggest that there is a high psychological and social burden of care on mothers of children with autism which could affect the health of the child being cared for. These psychological and social burdens are reviewed in this section by keeping in mind that knowing the challenges of these mothers will help in finding coping mechanisms for those challenges to reduce the burden of care on mothers and reciprocally improve the health of affected children.

Although both mothers and fathers may be impacted by raising a child with special needs as a group, mothers appear to be the most affected by the stressors that result from raising a child with a developmental disability since they are the main ones to care for the child (Boyd, 2007). Mothers of children with autism have to manage and cope with the various forms of severe impairments present in the child and tolerate the psychological, social and financial difficulties that come from their child's condition (Bello-Mojeed et.al 2013).

Further, the mother tends to have the first role in caring of child with autism disorder and consequently mothers endure greater psychological pressure than other family members in balancing children needs and having a normal life (Hossein, Ayyub, Jalil, Nafiseh, 2013). This is due to in many cultures men are seen as the head of the house and bread winner which indicates that mothers are seen to have a higher responsibility of child caring as compared to fathers who are expected to be busy working for money to feed the family (Joachim and Robert, 2012).

For instance, Gray (2002), found that when parents receive a diagnosis of autism for their child, mothers and fathers are affected differently. In Gray's study children's autism caused problems for the fathers too but they were unwilling to acknowledge that their children's developmental disorders had any personal effect on them. Mothers on the other hand did not attempt to hide their emotions and confessed that their children's disabilities had significant personal effects on them.

Likewise, in China, McCabe (2007), noted that a number of differences on the effects between mothers and fathers. Most mothers in this study expressed feeling like they have limited social interaction or activities, their life revolves around their child or that they have no life of their own, feelings of stress, worry, or depression in terms of the impact of the diagnosis on the parents.

By the same token, in most of the cases mothers become the nearer to the child with autism while father works harder to earn money consequently, the father becomes irritated at the demands of the mother to interact with a child and mothers become frustrated at the lack of involvement of their partners (Aadil et.al, 2014). As a result marital conflicts will emerge including fighting and separations which leads wives to believe that their husbands have not fully accepted the child's condition (Joachim and Robert, 2012). Several mothers attribute strain or

separation in their relationship with their partners to raising a child diagnosed with an ASD (Angela, 2013).

The data from phenomenological research exploring mothers' perceptions of effective coping strategies for their parenting stressors in USA by Heather et.al, (2010) and Montes, and Halterman (2006), on a survey study of Mothers of 61772 children USA mothers of a child with autism were more than twice as likely as mothers in the general population to report poor or fair mental and emotional health as a result of harder to care for their child and that they had given up more of their life than expected to meet the child's needs.

Similarly another Indian quasi-experimental research which examined the stress and coping experienced by mothers of autistic children and mothers of normal children having children between age group of 3 and 12 years by Nisha and Susan (2010), found that mothers of children with autism have been found to experience more stress while interacting with their children than mothers of normal children and the most dramatic adjustment to a child's special needs is made by mothers which leads them to a higher risk at surrendering to the effects of stress than fathers.

Another study by Smith et.al (2010), also indicated that mothers of children with ASD had significantly lower levels of positive affect, significantly higher levels of negative affect, and greater fatigue with more work intrusions. Likewise, In the United States, numbers of studies have found parents to report a negative impact up on their career after having a child diagnosed on the autism spectrum in which mothers reporting moderate to serious limitations on their careers, and denied any opportunity for outside employment due to their child's disability (Gray, 2002; Bayat, 2007).

Supporting this preliminary qualitative research conducted in China suggests that many families and mothers in particular, found themselves changing their work habits in order to better

meet their child's needs in many cases quitting their jobs and shifting to full-time advocacy (McCabe, 2007). In general, many Jamaican mothers also reported the impact of raising a child on the spectrum on their career such as work interruptions, having to leave early and having to quit their job in order to better meet their child's needs (Angela, 2013).

A search of the literature revealed a scarcity of data on the relationship between impairments in autism and the burden of care experienced by mothers of children with autism in sub-Saharan Africa (Bello-Mojeed et.al 2013). But the few existing literature shows that mothers of autistic children suffers from many psychological and social difficulties raising a child with autism.

The results of Bello-Mojeed et.al (2013), study where Sixty mothers and their children who had autism recruited from the Neurodevelopmental Child Clinic of Federal Neuro-Psychiatric Hospital Lagos, Nigeria showed that the higher the number of impairments present in a child with ASD, the higher the psychological and social burden experienced by the mother. The social type of impairment in this study was significantly associated with high levels of maternal psychological distress.

In another study by Lara (2007), that conducted a needs assessment of parents of children with autism in parents of children with autism who attend school in South Africa mothers mentioned the lack of support as a social challenge. The lack of government funding for special needs, the limited treatment options and limited number of people trained to work with children on the spectrum was a burden all these mothers experienced as raising a child with autism.

Likewise according to the report by Getnet (2013), parents of autistic children in Ethiopia, particularly mothers will be burdened with the full responsibility of care and their child's

disability directly constrains their ability to work and make a living; to take care of their children and themselves which create emotional and financial problems for the mother.

2.6. Coping Mechanisms of Parents Raising a Child With Autism

Understanding how parents of children with ASD cope with the daily stressors associated with raising their children is beneficial for many reasons (Colin and Kathleen, 2008), including better parenting of the child and its help to decrease the unnecessary institutionalization of countless children (Boyd 2007).

A number of researches that the student researcher reviewed identified coping strategies parents employ to cope with the stressors of rearing a child with ASD. There was no one strategy found to be successful for reducing or coping with parental stress rather several coping mechanisms was found to be effective. Thus some of the common coping strategies across recent literatures are discussed in this section.

As Nabawy and Ahmed (2012), pointed out coping involves psychological and social resources and strategies that help to eliminate, modify, or manage a stressful event. From the student researchers' point of view, as seen in previous literatures having a child with special needs creates a stressful event, how mothers respond to the stresses of raising their child with special needs depends on a wide variety of factors influencing their ability to cope.

The age of the parents, number of children, civil status, their interpretation of the crisis event, the family's sources of support, community resources, and education of the parents are from the factors that affects the kind of coping mechanisms employed by parents (Durban et.al, 2012).

2.6.1. Social Support

Social Support (seeking assistance) is the major coping mechanism that is found to be moderating parenting stress and daily negative mood (Colin and Kathleen, 2008). Supporting this, a study by Lori (2008), described social supports significantly contributed to reduce family stress and resulted in family coherence.

Parents of children with autism need support to assist them emotionally and physically by being provided resources (Myers, Johnson and the Council on Children with Disabilities, 2007). While the primary social support includes spouses, partners, neighbors, family, and friends who offer emotional and mental assistance informal support on the other hand involves other parents of children with autism and local organizations that give instruction, guidance, respite care, and social events (Myers et al., 2007).

A phenomenological research which explored mothers' perceptions of effective coping strategies for their parenting stressors in the North eastern United States by Heather et.al (2010), also demonstrated that participation of their spouses in the parenting was critical for mothers as they split the responsibilities and felt a sense of relief knowing that in their spouse, they had someone who they could relate to as a significant emotional support.

Jamaican mothers involved in Angela's (2013), study reported having social support helped them to attain needed information on the spectrum and reduced their stress by sharing it to professionals and other mothers who have a child with autism. In the same way Altiere (2006), demonstrated that families in his study relied on other parents of a child with autism for support and that they gained some valuable friendships by meeting other parents with a child with autism. Generally, many parents stated that meeting other parents of children with ASD was

beneficial to feel less isolated and that strategies should be put in place to facilitate this (Murphy and Tierney, 2007).

Other studies by Gray (2002); Montes, and Halterman (2006); Boyd (2007); Pottie and Ingram (2008) and Latefa (2014), found that parents of children with ASD who have a strong social support network demonstrated a greater ability to cope and adapt to new and challenging situations.

Altiere (2009), maintained that mothers were more likely to report that their family seeks social support during times of crisis than fathers because it gave them confidence and perception of a low stressed lifestyle. Supporting this Boyd (2007), reported for mothers, as opposed to fathers, the perceived usefulness and availability of the social support network play a vital role in lessening stress as a result mothers most often want, and first seek, support from their spouses.

Correspondently, according to a Philippines study by Durban et.al (2012), mothers tend to get closer to the family for support while the male slowly created distance between him and the family because they do not know how to handle the situation and sometimes would have the feeling of blaming their wife for the disability of their child.

2.6.2. Coping Through Religion

Participation in religious organizations was another positive coping strategy (Gray, 2002; Pauline, 2014). Several families found extensive support from religious organizations and felt that their spirituality was enhanced because of their situation (Altiere, 2006; Joachim and Robert, 2012).

The findings from Tiffany (2010), shows that being involved in a Bible study assisted participants in developing patience, stress management, helped to deal with the obstacles that come with their child's autism and in the healing of their child. Similarly in a study by Durban

et.al (2012), parents were able to find comfort in religion because it can give them strength to continue to go on with their lives despite the challenges they face with the extra burden of taking care of the child with ASD.

The result of Latafa's (2014), research also showed that positive reappraisal and spirituality was the most commonly used coping strategies among Jordanian parents raising a child with autism. As illustrated in this study the high reporting of the use of positive reappraisal as a coping strategy may be due to the Jordanian culture where one need to believe in God's will and pray to bring comfort and calm.

From the student researcher's point of view coping through religion might be usually used by many Ethiopian parents of children with autism due to the fact that many Ethiopians are religious that they might often seek religious methods such as holy water and prayer and as a result of the scarcity of institutions that provides intervention for those children and other supports for the parents.

2.6.3. Resilience and Positive Appraisal

Mothers of children with autism have been found to use positive appraisal (creating a positive out of a situation) as a coping strategy more frequently while dealing with the stressful situation of having a child with autism by focusing on personal growth (Nisha and Susan, 2010).

In Kristen's (2008), phenomenological study which explored what meaning does raising a child with autism have for parents participants made reference to a number of positive changes in their lives that is attributed to cope easily with their children's situation such as a reevaluation of their general outlook on life such that they had become mentally stronger; more resilient in the face of stress; and more appreciative of life and the small things that can make them happy.

Consistent with Kristen's study Altiere (2006), described conceptualizing the event of raising a child with autism is an integral part of parents' ability to cope with the struggles they face every day. Parents in this study supposed if they dwell on a negative attribution of this event, it is likely that they will cope poorly with the situation.

Likewise, Sivberg (2002), identified in the participant's interview responses the parents demonstrate flexibility, problem-solving, patience, unconditional love and understanding qualities which have enabled them to emerge from the strain of parenting their children with dignity and resilience.

Supporting Sivberg Bayat's (2007), survey with 175 parents of children with autism ranging from two to eighteen years of age to examine the evidence of resilience in families of children with autism, provides evidence that, despite extraordinary challenges faced by families of children with autism, a number of these families show evidence of resilience. Bayat determined that *"families who demonstrated resilience (the capacity to endure adversity while becoming stronger and more resourceful as a result) had a greater ability to cope with their child's ASD."*

2.6.4. Acceptance, Adaptability and Normalization

Lori's (2008), phenomenological study found that when first learning of the diagnosis parents experienced a sense of loss, grief and faced other negative impacts due to autism; however, they were able to prevail and overcome their many challenges and their first step in recovering from their grief was acceptance and understanding.

Research shows that families who have moderate levels of cohesion and adaptability have higher levels of positive coping (Altiere, 2009). Another study by Lara (2007), stated that a positive attitude and acceptance of the autism diagnosis were important aspects of getting

through the day for the participant mothers which enabled them to find appropriate interventions and education for their children.

By the same token, Kirsten (2008), demonstrates in her study acceptance was an important part of these parents' experiences that facilitated their ability to cope with their child's autism. For some of these parents in Kirsten's study though, acceptance is not just about being able to accept the autism, it involves being able to accept and adjust to all of the additional things that come along with autism, such as the fact that it is not a condition that will go away, and indeed will continue to present challenges as their child develops.

Finally in a Sweden study Sivberg (2002), concurs that a strong sense of cohesion and acceptance had a strong stress reducing effect regardless of a severe life situation as a parent of a child with autism. These parents reported that they developed their adaptability as they educated themselves and learned new strategies to create a cohesive family unit which enabled them to adapt to life's difficult situations.

2.6.5. Information and Knowledge

Information about specific areas of impairment associated with burden of care in autism could help in designing and implementing appropriate interventions to help mothers understand and cope with the behavior of a child with autism (Bello-Mojeed et.al 2013).

Lori (2008), indicated that parents experienced a sense of relief with having knowledge and information about autism. They demonstrated educating themselves about autism helped them to better understand their children's behavior and could also plan for the future. As well Sivberg (2002) and Heather et.al, (2010), suggested that parents need to fully increase their knowledge about the phenomena of autism in order to effectively manage the upbringing of their child

because knowledge equals power and can motivate parents to be the greatest asset to their children.

Harmoniously, more than half of parents reported that information related to resources, treatment, coping strategies, and prognosis were helpful in Angela's (2013) study, in terms of what was the most useful source of information to them, they reported information from family services workers, local support groups, as well as workshops and early years courses offered by the support groups were the most helpful sources of information.

In addition, Murphy and Tierney (2007), in their study of parents' need of information and education about autism in Ireland consisting 27 mothers and 11 fathers indicated that information was used by parents in this study to gain a greater sense of control over child and family outcomes. The majority of parents reported that other parents of children with autism and the internet were their greatest sources of information and emotional support.

South African mothers in Lara's (2007), study also had different coping strategies to enable them to get through each day with a feeling of proactive and gave a sense that something could be done. One of these coping strategies was providing themselves with knowledge and information about autism.

To summarize, the above literatures clearly indicate that social support, religion, information, acceptance and adaptability are effective coping mechanisms for parents of children with autism to better be able deal with the challenges raising their special needs children.

2.7. Theoretical Framework

As previously seen in this chapter raising and supporting an individual with autism is challenging as it have the potential to strain family relationships and the overall wellbeing and functionality of the family by creating stress associated with daily tasks and parenting

responsibilities that lead to worry and frustration. Several literatures mentioned in this chapter also stated that this parental stress, worry and/or frustration may simply be due to lack of knowledge and understanding of the society about the disorder or parents lack of ability to obtain information about autism which, in turn can impact the emotional state of the parent themselves, the individual on the spectrum and the environment in which they all live.

Therefore, understanding how environmental issues facilitate in establishing the emotional and physical wellbeing of families of children with autism as it relates to the child's development which include parent involvement and other ecosystems will be essential. Thus, this thesis relied on Ecological theory (Bronfenbrenner, 1979) for its theoretical framework because its explanations on how children influence and are influenced by the institutions in their environments including their familial, educational, religious and other supporting settings shapes their development is well-suited for a research that focuses on how psychological, social challenges and coping mechanisms of mothers that have children with autism spectrum disorder influence the daily lives of those mothers and their children.

The ecological paradigm in human development can be traced back to Bronfenbrnner's work in the early 1970's which looks at a child's development within the context of relationships that form their environment (Bronfenbrenner, 1979). This theory defines complex layers of environment each having an effect on a child's development. The interaction between factors in the child's maturing biology, their immediate family/community environment, and the societal landscape directs their development and changes or conflict in any one layer will flow throughout other layers (Catherine, 2011).

The model also postulates that human development occurs as the person actively and reciprocally interacts with the various ecological contexts over time which incorporates; several

levels of ecological context; developmental processes or the relations between the individual and the environment; the person's biological, cognitive, emotional, and behavioral repertoires and various time dimensions (Behav, 2007).

Thus, Bronfenbrnner's theory of human development have implications for an understanding of the nature of autism as it describes human development, including that of persons with autism, occurs in the context of multiple dynamic transactional systems, with both immediate and more remote environments affecting the individual with autism (Behav, 2007).

In addition to the direct effects that can occur on a child with autism by interaction with the environment, there might be indirect effects as interactions among the various levels of the ecologies themselves can reciprocally and dynamically transform those ecologies (e.g., parents and providers can affect social policy that then affect the child's more immediate environment and the child him or herself) (Behav, 2007).

When considering the lives of children with autism and services for them in relation to the ecological theory, there are several levels of the environmental ecology that interact with each other including family members, various service providers, the immediate community, the larger society, and culture as well as the child, in a transactional manner. These ecologies provide the context that can be either facilitative or non-facilitative to the development of the autistic child as the child interacts with these environments and is changed by them; changes in the child with autism can also produce changes in the various levels of the social ecology (Behav, 2007).

For instance, the behavior of the child will have an effect on the behavior of parents, friends, child care staff, etc. and their behaviors will affect the child, thus, a child displaying a disruptive or aggressive behavior (a child with autism) is more likely to elicit restrictive or

punishing parenting behavior, while a friendly and attentive child is more likely to evoke positive reactions from the environment (Sameroff and Fiese, 2000).

The human ecology model of human development proposed that five layers of influences impact a child's development: microsystem, mesosystem, exosystem, macrosystem and chronosystem and each system contains roles, norms and rules that shape an individual's development (Catherine, 2011).

The microsystem, the most basic ecological level, is the immediate temporal setting in which the child interacts with the environment. The child with autism operates in various microsystem structures and processes in the home, school, and community (Behav, 2007). According to this theory, if the relationships in the immediate microsystem break down, the child with ASD will not have the tools to explore other parts of his/her environment, thus impacting his/her development and causing more deficiencies (Catherine, 2011).

This theory further postulates that children with autism are dependent upon their microsystem environment beginning with the family, extended family, school, church and other community agencies that provides support and treatment (Marsena, 2012). Factors at the micro-system level can directly affect caregiving for children with disabilities, such as parenting practices and parent-child relations therefore, it is important for practitioners to assess factors that affect parenting practices and parent-child relations considering these are salient factors at the microsystem level (Churchill et al., 2010).

Churchill et al. (2010), further argues since caregivers of children with special needs are at increased risk of stress, depression, negative emotional state, and marital conflicts, which could undermine parenting practices and parent-child relations counseling and intervention strategies

that reinforce appropriate coping strategies and self-reliance can foster a sense of empowerment, which can potentially lead to better parenting skills.

The second layer of the ecological model, the mesosystem, is described as a system of microsystems that provides the connection between the structures of the child's microsystem and is the interactions and influences among major settings which is inclusive of the microsystem parts and how they work together (Catherine, 2011). 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, 2001).

Thus, understanding factors associated with caregiving for children with special needs necessitates an examination of the interactions at the meso-system level as a meso-system comprises the interactions or interrelations among two or more micro-systems i.e. experiences involving one micro-system (e.g., caregivers' marital relationship, religious and social support) may influence another micro-system (e.g., caregiver-child relations) each of which can affect the child with the developmental disability (Algood, Cynthia and Hong, 2013). Religion as a social support also is another meso-system-level utilized by caregivers of children with disabilities that is related to positive outcomes that can influence the quality of parent-child relations (Algood, Cynthia and Hong, 2013).

Exosystem the third level of the ecosystem that has an indirect influence on the child with autism via their direct impact on other persons who, in turn, interact with the child (e.g., linkages and processes among various contexts in which parents and service providers may interact without the child).

Other more distant relations that affect the child with autism and the parent indirectly are found in the exosystem which includes not only larger social institutions such as community support and health services, but also other structures such as the world of work and mass media that operate on the layer (Petra, 2012).

The macrosystem is the superordinate environmental level that subsumes the other ecological levels that affects human development at the societal, ideological, and cultural levels (Lerner, 2005). Societal regulation and cultural values affect children with autism via state and federal legislation, judicial opinions, governmental administrative regulations, health insurance practices, and other societal behavior directed toward them (Behav, 2007). For instance, parents' allowance may enable parents to stay at home with the child on the spectrum during infancy and later access to child care outside the home that may promote the child's social and language development and allow for parents to participate in working life (Petra, 2012)

Therefore, as findings suggest 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).

Finally the chronosystem consist the transactions between the organism which is the child with autism and the factors we mentioned in the environment over time (Behav, 2007).

Generally, a number of studies have shown that poor parenting quality has consistently been found to be associated with negative outcomes of children with disabilities (Milshtein et.al, 2010) and factors affecting parenting practices for children with disabilities are complex and

multi-faceted, which provides a rationale for ecologically based practice implications in order to provide appropriate intervention strategies (Algood, Cynthia and Hong, 2013).

Hence, parents and service providers should work collaboratively in their microsystems to form a contented mesosystem, implement services in a consistent manner and service providers should address the many family needs by working collaboratively toward affecting societal behavior and public policy (the macrosystem); For example, parents, professionals, and service organizations could collaborate to exert contingencies on state legislators to appropriate funds to create professional training programs related to autism (Behav, 2007).

Thus, a model of effective services for children with autism should identify the relevant levels of the child's ecology, target each level for intervention in a comprehensive autism program and address how those levels can be positively influenced by the autism program (Behav, 2007). Further, Behav (2007), described that comprehensive autism programs should engage in strategic planning to determine how to promote transactions among multiple ecological systems, for example, child, family, human service organizations, governmental units, and society at large and new services and activities should be initiated to create strategic transactional impacts that will enhance the life of children with autism and their families.

From the student's point of view, applying Bronfenbrnner's theoretical perspective described above on families of children with autism contributes important knowledge about the passage of transactions between parents and their children with autism, and how they affect each other.

2.8. Summary and Implications

To summarize, the recent literatures reviewed by the student researcher harmoniously shows that diagnosis of a child with autism is a much desired process by parents to know what

exactly differs the development of their child from other children. However, late appearance to health care institutions and late diagnosis is reported by studies from Africa than western studies. These literatures also indicated that most parents felt the diagnosis process as frustrating and shocking which leads them to want being provided with more detailed information about autism than they had provided with during the time of diagnosis to take further actions.

In addition, reviewed articles regarding to the cause of autism presents controversial causes which include various genetic and biological cases as well as environmental ones. From these complex genetic interactions, nutritional deficiencies, pre- and post-natal exposure to chemicals, viruses and/or teratogens are found to be common explanations for the causes of autism.

However, parents' explanation about the cause of their children's developmental disability differs across studies from different countries. Parents from well developed country raise more logical and near to scientific explanations where as parents from less developed and developing countries specifically from Africa raise more cultural and non-scientific explanations.

It is clear from the literature base that parenting a child with autism is multifaceted that brings challenges for the parents to become at risk for negative psychological and social outcomes whether it is about the way they care for the children, their day to day life with the child, the future of their child, high levels of emotional stress as a result of their child's autism, fatigue on caring of the autistic child, marital stress, impaired social engagement, career problems and isolation from the society.

The literatures that the current research reviewed does not show that parents and primary caregivers of children with autism are less challenged today or have better, more efficient ways of coping than they did years ago. Further, it can be gleaned from previous studies caring for children with autism constitute a significant source of burden on mothers of affected children

than fathers and impairment in childhood autism has a direct relationship with maternal psychological and social burden of care.

However, recent studies show that over time most parents will identify coping strategies that work for them and adapt to the experience of having a child with autism. Though, Coping strategies and resources designated in chapter two produce an accurate list but lack the description of the process that the parents go through to have inner growth and the adaptation process they endured.

The implications of these literatures that are reviewed in chapter two are enormous. First, most studies reviewed provided rich and descriptive information on firsthand accounts of the lived experiences of actual families particularly mothers effected by autism which allows us to better understand, using lived experiences, what it is like to be a parent of an autistic child, and what that experience means. Since autism is an issue that still needs much exploration in our country the various reviewed studies across the globe will add more information regarding autism to the body of the current study and will give the audience a better ability to gain knowledge of the feelings, motivations, challenging experiences and coping mechanisms of raising a child with autism across cultures.

Second conducting literatures targeting mothers at risk will go a long way in reducing the burden of care on the mothers and reciprocally improve the health of affected children and the society at large. For instance, the literature on the direct relationship between autistic impairments and burden experienced by the mothers support the need to incorporate the screening of affected mothers for psychological distress into the assessment of their child and level of support required by mothers caring for such children. Moreover, it can be concluded from previous studies that both informal and formal family supports and services are needed to

assist parents in relieving stressors that may be present in their homes and professionals can effectively support parents by helping them learn to use positive coping techniques to deal with their daily psychological and social challenges.

Additionally, the researcher hopes that by synthesizing the literatures conducted looking at the experiences of mothers of children on the spectrum, a more holistic view of the kinds of interview questions to the current study and identifying gaps in the current literatures has been provided.

Chapter Three

Methodology

3.1. Research Design

As remembered from chapter one the purpose of this study is to investigate the psychological and social impacts on mothers which come from raising children with Autism spectrum disorder and the coping mechanisms they use to deal with those challenges thus, a qualitative research was identified as the most appropriate to meet the research aim. This is due to qualitative research is suitable when researchers aim to understand how people experience events, how they make sense of their experiences and to reflect on their experiences (Deborah, 2012).

Similarly, Joanna and Alison (2006), indicate that qualitative research advances knowledge through a series of detailed, small-scale studies which embraces how people construct meaning to a shared understanding, feeling, or perception of a situation. Therefore, a qualitative design was identified as the most appropriate to meet the research aim of exploring the meaning, challenges and coping mechanisms inherent in the experiences of mothers raising a child with autism deeply with small participants.

Specifically, the researcher employed phenomenological research design to guide this thesis in accordance to the research questions because it is particularly effective at describing how things are experienced firsthand by those involved (Martyn, 2003).

By keeping in mind that phenomenological research is an in depth examination of an experience, directed toward obtaining meaning from the everyday lives of participants, especially those aspects relating to people's feelings about an issue, event, or experience (Deborah 2012), this study is intended to produce an understanding of the ways in which the participants deal with the psychological and social challenges of their everyday life as mothers of

children with autism and what mechanisms they further use to create a harmonious, coherent family lifestyle which is supportive for their children with autism.

Denscombe (2003), indicates that a phenomenon in a phenomenological study is a variable that is experienced directly, rather than being conceived in the mind as some abstract concept or theory that stands in need of explanation. Therefore, psychological, social challenges and coping mechanisms were assessed as phenomenon (variables) that are in need of explanation as experienced directly by the mothers of children with autism and conclusions about these phenomenon's was made in this study.

3.2. Study Site

The participants recruited for this thesis are mothers of children with autism spectrum disorder that diagnosed their children at Addisu Michael higher psychiatric clinic. Addisu Michael higher psychiatry clinic is a private clinic found in Addis Ababa that is providing assessment, diagnosis, inpatient and outpatient medical (psychiatric) treatments and psychological therapies for many psychological and developmental disorders including autism spectrum disorders for the past twelve years. As the director of the clinic Dr. Yonas indicated the clinic has twenty six staffs including two fulltime psychiatrists, 4 part time psychiatrists, one clinical psychologist, two general psychologists, one social worker, an art therapist, three psychiatric nurses and twelve general nurses. The clinic provides diagnosis for autism depending on the diagnostic criteria of American psychiatric association DSM-5 using verbal and nonverbal clinical tests 4 days a week (Monday, Wednesday, Friday and Saturday). The clinic also provides psycho-educational and medical therapy for the children with autism and family education training for the parents as well.

3.3. Participants

Since the focus of this study is to investigate the psychological and social challenges as well as the coping mechanisms that are employed to deal with these challenges by mothers with autistic children the target population were mothers of children with autism who diagnosed their children on the spectrum at Addisu Michael higher psychiatric clinic.

In Patton's view (1990), all types of sampling in qualitative research focuses on nominating relatively small samples even single cases, selected purposefully with a broad general knowledge of the topic or those who have undergone the experience and whose experience is considered typical. Specifically, phenomenological study suggests sampling to be purposive and broadly homogenous as a small sample size can provide a sufficient data on a given phenomenon (Joanna and Alison, 2006). Therefore, purposive sampling was used to recruit five to eight participants which are the recommended sample size for research of this kind (Creswell, 2007) that can provide sufficient data on their experience of dealing with the challenges they face while raising children with autism.

In addition, Creswell (1998), detailed that participants in a phenomenological study need to be carefully chosen to be individuals who have all experienced the phenomenon in question, so that the researcher, in the end, can forge a common understanding. As a result the researcher choose purposive sampling to identify the primary participants based on her judgment, the purpose of the research, needed sample size, resources and time available looking for those who have had experiences relating to the phenomenon to be researched and information-rich cases.

Specifically convenience (recruiting available participants) and snowball (where existing study subjects recruit future subjects from among their acquaintances) (Patton, 1990) methods were used in an attempt to reach more potential participants. The student researcher used

convenience sampling to recruit half the participants from Addisu Michael higher psychiatry clinic because they are available and voluntary to provide deep information with regard to the purpose of this study.

Snowball method was used while asking the participants recruited through convenience sampling to identify more individuals that could also be information-rich by possessing same experiences that are of the study's interest. Researchers suggest that using this type of approach to sampling enables researchers to identify a greater number of individuals affected by the phenomenon and also yields rich information about the social networks, grassroots of the individuals involved in sampling (Noy, 2007).

sample sizes in qualitative studies are often determined on the basis of theoretical saturation (the point in data collection when new data no longer bring additional insights to the research questions) (Englander, 2012) and small sample sizes are the norm in phenomenological research design as the analysis of large data sets may result in the loss of *'potentially subtle tones of meaning'* (Collins &Nicolson, 2002).

In addition, Phenomenological studies are not interested in "how many?" who have had a particular experience but how many times the phenomenon makes its presence in the description therefore, in researches based upon depth one could also use five or twenty participants, however it would most likely mean more work for the researcher and better appreciation for variation of the phenomenon, rather than better generalizability of the results (Giorgi, 2009)

Hence, the student researcher identified six mothers of children with autism that diagnosed their children on the spectrum who are aged from 7 to 16 at Addisu Michael psychiatric hospital who are information rich with respect to the phenomenon. As indicated before six participants are selected because Boyd (2001); Creswell (1998); Osborn (2007), regards two to 10

participants or research subjects as sufficient to reach saturation in phenomenological research design because the detailed case-by-case analysis of individual transcripts takes a long time, and the aim of the study is to say something in detail about the perceptions and understandings of this particular group which many researchers are recognized that this can realistically be done on this amount of sample size.

3.4. Tools of Data Collection

Semi-structured interviews were used as the main and most suitable data collection method as it allows the student researcher gather information with sufficient depth and quality to provide a detailed picture of participants' experiences on the challenges they faced raising children with autism and the coping mechanisms they used to deal with them. For instance, Turner (2010), indicated Interviews provide in-depth information pertaining to participants' experiences and viewpoints of a particular topic. Englander (2012), further argued that, Phenomenological researchers tend to choose the interview due to their interest in the depth meaning of a phenomenon as it is lived by other subjects.

The interview tended to be semi structured because semi-structured interviewing allows the researcher and participant to engage in a dialogue whereby initial questions are modified in the light of the participants' responses, the investigator is able to probe interesting and important areas which arise, it facilitates rapport/empathy, allows a greater flexibility of coverage, allows the interview to go into novel areas, and it tends to produce richer data (Smith and Osborn, 2007).

The researcher spent time engaging with some of the available literature published to compile interview questions that are directed to the phenomenon to be studied which are participants' experiences, feelings and beliefs regarding psychological, social challenges and

coping mechanisms when raising children with autism. The research objectives guided the interview questions in a way that will help to answer the research questions.

Open ended questions were used to give participants the opportunity to respond in their own words rather than forcing them to choose from fixed responses and to make the interview information rich and explanatory in nature. The interview questions were prepared in Amharic because it is a language that is comprehensible and relevant to the participants and the interviewer.

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).

Moreover, all the questions in the interviews were directly linked to the research's aim and covered all aspects of the topic. The questions were worded clearly and asked in a natural tone of voice. Any misunderstanding questions were repeated in order to enable the interviewee understand what she was asked for. Moreover, all interviewees had an opportunity to explain their own beliefs and thoughts freely without any interruption either with comments or gestures, which would create flexibility in the interviewee's response to the question being asked and reduce threats to the validity of the data that were obtained.

Member checking was also made to make sure the data that was generated was valid. During the interview, member checking was made with the researcher restating, summarizing, or paraphrasing the information received from a respondent to ensure that what was heard and recorded or written down was in fact correct. Following data collection, member checking consisted reporting back preliminary findings to respondents or participants, asking for critical

commentary on the findings and potentially incorporating these critiques into the findings because as stated by Newton (2010), both forms of member checking are fundamental process that affirms participant responses and validated emerging themes, which will enhance the trustworthiness of the study that adds accuracy and richness to a final report.

Therefore, when all the descriptions and themes were obtained, the researcher approached some participants through phone calls or physically depending on the participants' preference for the second time for further verification and validation of the findings. There were no suggested changes to the themes pulled from each mother's story except minor edits and all of the mothers engaged in member checks reported themes represented their story well.

Further, all interviews were recorded to present more reliable evidence and avoid any bias which might happen if the researcher attempted to remember the conversation as Gray (2004), asserted that *"in terms of reliability, it is fairly obvious that taped conversations will tend to present more reliable evidence than hastily written field notes".*

Seidman (2006), also indicated tape-recording offers to work most reliably with the words and thoughts of participants and to help researchers have their original data. Seidman further argued that if something is not clear in a transcript, researchers can return to the source and check for accuracy and if they are accused of mishandling their interview material, they can go back to their original sources to demonstrate their accountability to the data. Tape-recording also benefits the participants by assuring that there is a record of what they have said to which they have access can give them more confidence that their words will be treated responsibly.

Finally, to make the study more reliable and in the interests of clarity the researcher clearly outlined a depth description of the steps involved in this phenomenological study to give the opportunity for whoever wants to replicate the steps on the data can easily do so to find out how

reliable the procedure was. This is a technique by which a qualitative study can be evaluated or regarded reliable to check how and to what extent consistent methods and procedures are used (Shenton, 2004).

3.5. Procedures of Data Collection

The researcher scheduled the interviews after meeting all the parents in person and made sure that they are willing and can give rich information regarding their experiences of raising a child with autism. Throughout the researchers first visit she had a number of opportunities to engage with participants and build relationships with them prior to interviewing. It was felt that this rapport building prior to interviewing led to greater openness and willingness to engage with the researcher during the interview process. These experiences also allowed the researcher the opportunity to engage with mothers and their children to observe their interactions.

After wards depending on their preferences, the parents were interviewed at a time and location convenient to them which is their home for some and work place for others. An interview with each of them begun with briefing of the situation under which interviews came about to participants, purpose of the interview, and the use of a sound recorder. Participants then signed an informed consent form created by the researcher, indicating that the participant understood the risks and benefits of the study as well as the purpose of the study, the confidentiality of the information provided and their consent to participate in the study (See Appendix B).

The length of each interview ranged from two hours to three hours in some cases and data were collected over a three month period of time, where each family was visited at least twice. They were audio-taped to get all the detailed information that the researcher intended to investigate for a detailed analysis and to ensure that the interviewees' answers are captured in

their own terms. The participants were informed that they could request the tape recorder to be shut off at any point during the interview.

3.6. Pilot Test

The interview guide was pilot tested with two mothers from similar population after viewed by the academic advisor and other professionals prior to the interviews. Respondents were selected using the same method as the selection of the main participants for the pilot study to evaluate the adequacy and relevance of the instrument.

The pilot interviews were meaningful and appropriate to the aims of the study because they yielded adequate data necessary for theme identification and also showed the researcher that the interview would take approximately 1 hour to 1 hour and 30 minutes.

Most importantly questions that seem to hold repeated concept which lead to the same repeated answers and discussions, a question that both the mothers in the pilot interview didn't understood and another two questions that were totally irrelevant were reformed by combining the repeated questions and removing the irrelevant and misunderstood ones. It should also be noted that pilot questions seemed to be too restricted by its nature that produced restricted data from the respondents' interview hence final interview questions (Appendix A) reflect more broadly posed open-ended questions.

3.7. Methods of Data Analysis

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. The student researcher consider this method as appropriate because of its potential to

provide in depth insights in to subjective perceptions of the participants experiences about the phenomenon under study and this method of analysis interrelates to the research deign itself.

Supporting this Joana and Alison (2006) indicated that 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.

Further, Creswell (1998) stated that phenomenological data analysis proceeds through the methodology of reduction, the analysis of specific statements and a search for all possible meanings. Therefore, first the student researcher transcribed the tape recorded data by translating it in English noting the literal statements and leaving non-verbal and paralinguistic communications.

Each transcript was then read through in depth and were carefully checked against the audio-recording for quality, content and so that the researcher could further familiarize herself with the data and transcripts. Then significant sentences and phrases that were directly looking at the experiences of mothers of children with autism spectrum disorder regarding psychological, social challenges and coping mechanisms under study was extracted, and six coherent case stories were developed.

From the stories statements appearing significant to the interviewer in that they were mentioned by a number of participants or mentioned frequently for one participant were grouped together into larger units of information called themes and coded to identify commonalities among participants. Each participant's transcripts were highlighted with a color coding system to quickly identify these commonalities as they relate to each of the key topics. Anything interesting about what the participant had said was also noted as part of the initial coding process.

Then the researcher seeks to find all possible meanings, commonalities and divergent perspectives from these units of meanings. This is a process of getting at the essence of the meaning expressed in a word, phrase, sentence, paragraph or significant non-verbal communication in which crystallization and condensation of what the participant has said will be done by still using as much as possible the literal words of the participant (Creswell, 2007).

These formulated meanings were clustered into fourteen themes that were common to all participants' transcripts under the four research questions they addressed and were illustrated with exemplified extracts from the interviews on participants own words followed by analytic comments from the researcher in writing the results. According to Creswell, (2007) using interviewees' own words to illustrate themes enables the reader to assess the pertinence of the interpretations, and it retains the voice of the participants' personal experience.

Once all interviews had been individually analyzed, the identified themes was considered together and an overall group analysis was produced and discussed in the discussion part containing interpretative commentary of the researcher and supplementary findings from previous studies on the same topic.

3.8. Ethical Considerations

In order to ensure ethical research the researcher and the respondents had mutual informed consent to get detail information from parents and to keep the confidentiality of the information provided. Prior to conducting any interviews, including those in the pilot study, participants were provided with a description of the study and an opportunity to ask any questions. Then the student researcher asked participants' permission for their interview to be audio-recorded, later transcribed with the removal of any personal identifiers and they were informed that the audio recordings would be destroyed upon completion of the transcribing.

In addition to the verbal consent the researcher read the written consent form prior to conducting the interview. At this time, the researcher took a second opportunity to explain the study's purpose, the use of a digital voice recorder, the issue of confidentiality, and the use of pseudonyms to the participants. Participants were then given an opportunity to also read the informed consent form, ask any remaining questions they may have about the study, and provide their signature indicating their consent on the form.

The dignity of all research participants was respected to ensure that people not be used simply as a means to achieve research objectives and those who take on the burdens of research participation should share in the benefits of the knowledge and the aids that will be gained.

Chapter Four

Results

As stated in chapter one the major objective of this study was to find out the psycho-social challenges faced by parents of children with autism and the coping mechanism they used to deal with those challenges. Accordingly, this chapter presents the main research findings obtained from the interview process with all the mothers to discover the everyday lived world of the participants, which was combined with the researcher's data analysis or exploration of their experiences.

Therefore, first the participants' demographic information will be presented in table 1 and the mothers' stories about their suspicions and concerns that led them to the diagnosis of their children will follow on their own words to introduce us with each case. The other results will follow by being categorized in to the fourteen initial units of meaning (themes) that emerged from the raw data which are Sorrow, Shock and Feeling of Loss as a Reaction by the Mothers, Mothers' Lack of Information and Support During the Diagnosis, Being personally Changed as a Result of Children's Diagnosis, Mothers' Hypotheses Regarding the Etiology of their Children's Developmental Problem, Concern About Child's Future, Stress from Managing a Child with Autism, Busy Daily Schedule and/or not Having a Time For Oneself, Effect on The Family, Reactions of the Community, Difficulty Finding Education, Treatment and Support For Their Child, Religion, Educating Oneself About Autism, Social Support and Acceptance and Appreciating any Progress the Child Makes being guided by the four research questions.

Table 1

Demographic characteristics of participants

	Current Age of child	Age of child when diagnosed	Gender of child	Mothers' age	Mothers' educational level	Mothers' occupation
Mother one (Roman)	9	2	male	34	BA degree	Marketing manager
Mother two (Hirut)	8	4	male	40	High school complete	House wife
Mother three (Aster)	13	5	female	50	Agricultural diploma	Coffee tester
Mother four (Tsega)	7	4	male	35	High school complete	House wife
Mother five (Etagegn)	8	5	female	38	diploma	Secretary
Mother six (Tsehay)	15	9	male	58	Illiterate	Injera baker

* Each participant cited has been assigned a pseudonym to protect their identity

As can be seen in table 1 the participated mothers are middle aged mothers where four of them have a full time job in accordance to their parenthood. Further, the age that most of the children got diagnosed can be considered appropriate since the average age of diagnosis for participants children appeared to be 5.5 years similar to the age in different western literatures (i.e. National Autism Center, 2011; Tiffany, 2010) compared to other studies from Africa that

stated late diagnosis to be observed at the literature review (i.e. Bakare & Munir, 2011; Bello-Mojeed et al, 2011).

Mother one (Roman):

> Kidus is my second child with two siblings. Kidus had difficulty to sleep, he cries and screams extremely, he did not wanted to be hold by people other than me and had immense constipation as early as age one. I used to consider all his behavioral problems as he is an aggressive child until he approaches 1 year and 8 months but was curious of his behaviors being way too different than my first child. After wards I took him to a hospital for his Constipation problem and the doctor further suggested that I take him to a psychiatry hospital where I learnt that my child is diagnosed with autism spectrum disorder by a physician.

Mother two (Hirut):

> Eyob is my fourth and last son. I knew something was wrong with him because he can't speak, had difficulty sleeping and was very disturbing until the age he got diagnosed. I made a maximum effort to cure him before and after the diagnosis by taking him to prayers at the protestant church because most of the symptoms he showed were as of an insane person. Most of our relatives and neighbors thought he was sick spiritually and recommended me to take him to churches and places that give holy cure. I tried to make him participate in some activities at home but he usually doesn't follow instructions unless he is interested. He is still nonverbal but he understands what he is told. The child does not stop manifesting undesirable behaviors even if I try to control him other times he behaves as if nobody is around him. He usually screams at, scratches and beats anybody around him and he gives less response to playful interactions with others.

Mother three (Aster):

> Tina is a third and last child for me. She is a very beautiful and affectionate girl. I knew something is wrong with her since she was 2 and a half because her development was not as of my older two children. Her hands and legs were too short and her face seems not normal too. She was not able to talk and walk either she didn't want to approach with other people, she cries and screams a lot specially if she got disturbed from a routine thing she does. I took her to children's clinic at age 3 and they told me that she was mentally retarded. I didn't go to another medical institute until she reached 5 and her symptoms started to get worse. After wards a friend told me about this clinic and I took my daughter to do some tests. The doctor told me she got diagnosed with autism and her situations can be improved if I treat her well and if I spend a lot of time with her to train her.

Mother four (Tsega):

> Aklil is my second son and a very handsome boy. We had no clue and thought that he will be autistic because he was great until he turned 2. The first suspicion was from me noticing he was a bit late to speak but my husband's mother told me that his father was late to speak too so we thought it was normal. Afterwards he begun to be prone to self-injury like biting his own hands hardly, he didn't respond to his name or don't respond at all, he usually acts if he weren't hearing, he used to do the same things over and over again and he would be extremely upset if we tried to move him from that activity he could even knock himself to the wall by age 4. Then we took him to a hospital when our suspicion becomes stronger as a result of his behaviors getting worse.

Mother five (Etagegn):

> Muna is the first child for us out of two children. I already knew she had a problem because she never interacted with other children she can't use toilet or eat by herself at age 4. After wards we tried to get her to kindergarten school but she kicked, screamed, cried and was difficult to handle. Then a relative told me to take her to hospital. I took her to a nearby private clinic and the doctor told me to take her to a bigger hospital because he guessed my daughter's condition could be a series mental disorder. She got diagnosed three years ago and I was told that she had a developmental disorder called autism by the professional who I don't exactly know whether he is a psychologist or a pediatrician.

Mother six (Tsehay):

> Sintayehu is my first and only child. I already guessed something was wrong with him but I never thought it would be autism because I never heard what autism was in our country. He does not look or respond when I called his name. I was worried that he was going to be deaf so I took him to a doctor at Tikur Anbesa hospital but they didn't find anything wrong with his ears. When he does talk his words are hard to understand. He spends a lot of time playing alone and sometimes becomes very upset if someone from the neighbor tries to be with him.
>
> He is hard to handle and has started getting very upset often, especially when his day changes and something different happens. When he becomes upset he screams loudly and stomps his feet and Sometimes makes loud noises for no reason at all. I'm feeling more and more helpless and frustrated until now. He also acts out in public which makes me feel ashamed and embarrassed. I love my son very much and I tried hard to do all I can for him. I asked plenty of people for help and advice but it seems everyone has something different to say. After wards a very nice woman that I worked at as an Injera baker twice

> a week wanted my son diagnosed and wanted to see if there are treatments that can help him when he reaches 9. We took him to the clinic you found me at taking his pills, and they said he has children's disorder called autism which can't be cured but they prescribed a drug which they say that will make him less aggressive and calmer.

From the above mothers' stories about their suspicions and concerns that led them to the diagnosis of their children it can be gleaned that almost all the mothers similarly had some concern about their children being a special needs child before they made a medical assessment and they are the first to notice something different. Thus the other results are presented as follows by being categorized in to the themes that emerged from the raw data being guided by the four research questions.

4.1.The Major Reactions and Experiences of Mothers during the Time of Their Children's Diagnosis

The first research question focused on the journey of the mothers on the diagnosis of their children for Autism spectrum disorder. The purpose of this research question was to better understand what the journey to and the diagnosis process was like for mothers as well as to comprehend their perceptions regarding etiology of their children's developmental disorder.

4.1.1. Sorrow, Shock and Feeling of Loss as a Reaction by the Mothers

The researcher was first interested in learning about the initial reactions of the mothers at the time of diagnosis. Although mothers demonstrated a range of emotions immediately following the diagnosis, the most prominent reactions all the mothers similarly went through were despair, sadness, shock, confusion and/or feelings of loss which led to the emergence of the first theme Sorrow, shock and feeling of loss as a reaction by the mothers. For instance, Roman said,

> I was really heartbroken and sad by the time the doctor told me that my child has been diagnosed with an incurable developmental disorder that will be with him for a life time. It was like bereavement how I took it and how my friends were calling and saying they are saddened by the news they heard etc…. I was absolutely devastated at the time and lost appetite for weeks after the diagnosis knowing my child is not going to be in a way that I dreamed of. I thought why me, what did I do wrong to deserve this. I was relieved to have the word for his problem but at the same time I felt really sad for my son to have this lifelong disorder. Generally I can say I go through all the emotions from feeling of loss, sadness, guilt, shame, and confusion.

However, Tsehay differed from the others by not being surprised by the time she learned her son has autism from a professional saying,

> I knew I had a sick son since he was little and everybody around (my neighbors) knew too because it can be seen on his face and he can't talk either. That made me not to be surprised by his results of the diagnosis. I was sad ever since he was little about his condition.

It was found that the above feelings the mothers encountered after the diagnosis were difficult due to the fact that they had no or little prior knowledge about autism and they were not fully informed at the time of diagnosis rather they were left alone to educate themselves about different aspects of the developmental disorder including treatment options which emerged the second theme mothers' lack of information and support during the diagnosis.

4.1.2. Mothers' Lack of Information and follow up during the Diagnosis

Most participants similarly reported that they were not empowered with information by professionals at the clinic before or after diagnosis which worsened the hard feelings they had as a reaction. For example, Aster explained that she didn't know about the developmental disorder except for its name since autism was not as prevalent as it is now and it was her responsibility to seek answers in relation to the causes, and available treatments for autism from books and recently from the internet.

Tsega also clarified that not being aware of what autism was and the shortage of information about the prognosis, causes and cure of her child's spectrum except for the recommended medicine to address her child's challenging behaviors which he is taking that until now made it harder to accept her child's developmental disorder. Finally Roman further stated that she felt hopeless by the way and the words the physician used to tell her about her child and she had no choice other than to search for information on her own as a result of the shortage of information and support during the diagnosis.

The discussions about the experiences and reactions of mothers' at the time of diagnosis led to questions of what they did next in terms of supporting their autistic child. It was found that once the mothers had processed their initial grief they took different measures to help their child, for some trying to find medical help was a way like Roman explained,

> The next step I made was trying to find medication for my child in which I tried to get out of my country to find advanced intervention which didn't work out anyway because I couldn't find any medical service here in Ethiopia except the drugs that are prescribed by the physician that made the diagnosis of my child. Then I tried to read a lot and educate myself to take some measures instead of crying and losing hope. (Roman)

Other mothers turned to religion to get cure for their children's problem and others treat their children themselves by being close and staying home teaching them. As Tsehay said; *"My next step was taking him to the holy water like I used to do before the diagnosis."* And Aster explained,

> My next step was leaving work fully and starting to take care of her and home teach her by beginning with the necessary skills that a five year old should acquire even if it was too difficult and it's like a whole new journey. I decided to take my daughter to monasteries and churches continuously to cure her through holy water.

As the mothers discussed how they began taking steps moving from the overwhelming feelings after the diagnosis to taking further measures to attain the best help for their children

they reported feeling of being changed positively in a number of ways as a person and as a parent which lead to the occurrence of the third theme being personally changed as a result of children's diagnosis.

4.1.3. Being personally changed as a Result of Children's Diagnosis

Most of mothers similarly mentioned that having a child with autism changed them positively in which they become tolerant, patient, being less judgmental and sympathetic for other people and appreciative of little things over life. In some cases participants also described that their experiences with their autistic child had increased the level of closeness on their family. For instance Etagegn said,

> I've become more tolerant and more sympathetic to people that have a special needs child and any other persons with disabilities, I now know what they're going through because if you have gone through this you know what they are going through. In some ways it makes me much more appreciative of little stuff that my daughter does.

Aster further said,

> My parenting style has changed in a way that I gave the most attention and care for Tina that I didn't gave for my two older children. She made me to care more for my other children being grateful to God that they are healthy. But the most important thing I have developed is patience. Tina's behaviors were so hard to deal with so I chose to be patient with my child's progress even if it can be very challenging at times.

4.1.4. Mothers' Hypotheses Regarding the Etiology of their Children's Developmental Problem

Finally the researcher was concerned about the mothers' perception as the cause for their children's developmental problem under the first research question because from the researcher's point of view their belief about the causes can be interrelated with the kind of coping mechanisms they use to better cope with the difficult behaviors of their children and other challenges they faced. Nearly all the mothers thought as they have been intended by God to have a special needs child as their hypotheses because they didn't do anything wrong during their pregnancy time that can be considered as a threat to the fetus. For instance, Hirut supposed,

> I think It was intended by GOD for me to have a child with autism because I didn't do anything wrong by the time of pregnancy, during birth and after birth. I did the same things I did with my older healthy three children during pregnancy and after birth.

However, one mother (Tsehay) differently reported her child's disorder could be a result of her age being late to have a child saying,

> I sometimes think it could be due to my age when I got him. I mean I was too old to have a first child at age 43 but I thought I will have someone to support me at my elderly days which didn't turn out to be as I thought anyway (ጧፊ ስገኝስሁ ብዮ ተጧፊ ጠለዮኩ).

After wards the student researcher and the participants move to discuss questions under the second research question that examine the psychological challenges the mothers faced raising a child with autism and the following some most prominent themes about those challenges were extracted from the testimony of the participants.

4.2. The Psychological Challenges faced by mothers raising children with Autism

The mothers spoke of several psychological challenges they endure when raising their children on discussions with the student researcher and permanent worry about their children occurred to be the main psychological challenge which emerged the first theme under the second research question that is Concern about child's future.

4.2.1. Concern about Child's Future

When discussing about the psychological challenges the participants faced while raising a child with autism worry over the future of their children as who would care for their children when they no longer can be there for them and what the future would hold for their children appeared to be the major source of anxiety for all the mothers. For instance, Aster explained,

> The thought of my child's future is the main thing that worries and stresses me by being in to my mind permanently. I always think what is going to happen to her when I can't be

> there for her. This child is going to outlive me because she is physically fine so who is going to take care of her? Yes I always worry about Tina and her condition. The fact that her disorder can't be cured makes anxious about her future over and over again. I am also devastated by knowing that she can't get married and start a family of her own because of her situation.

And Tsehay further added,

> I don't know what to hope about my son's future. Sometimes I hope that God takes him before me (እግዚአብሄር ከኔ ያስቀድመው እሳስቡ). I know you never heard of a mother wishing her child to be dead before her but it's just because I don't know what, where and how my son would be if something happens to me since I am the only family and relative he has got. I can't stand imagining him afraid alone being on the streets starved when I'm gone. If sometimes Sintayehu behaves bad and try to hurt himself I take control of him but I think about when I get older, physically, how am I going to manage him? .

Most of the mothers also reported they had to redefine their hopes about their child's future after knowing their child is a special needs child but they still hope if their children be functional and get through all the normal activities that every child goes through. For example, Tsega indicated:

> My dreams were that my son would go to college, get a great job, find a spouse, have kids, and I would be a grandparent. Those normal hopes were turned upside down. Now I hope if he could have a good education and go as far as his abilities can take him like everybody does, hold a job. I hope nobody take advantage of him because of his disability. So my main aim now is getting him into school with other kids. I hope that one day he will actually register to be educated.

While talking about the mothers concern for their children's future that was further aggravated due to their children's difficult behaviors that are hard to manage several other stressors the mothers encountered in accordance to raising a child with autism come along to discussion which contributed to the second theme under this research question that is stress from managing a child with autism.

4.2.2. Stress from Managing a Child with Autism

Most of the mothers that spoke with the researcher stated that managing their children's behaviors can often be challenging and stressful. For instance, Tsega talked about her son's unpredictable tantrums as challenging saying,

> His unpredictable behavior is sometimes a challenge. With other disorders parents can predict what their child's behavior is going to be like but with autism there is no telling about what the child is going to manifest. I feel frustrated when I think Aklil has understood what I told him but in the next minute he does the opposite.

Aster further talked about how she feels bad when her daughter becomes upset and injures herself. She said,

> Her behavior is challenging to handle especially if she gets upset or when someone wants her to do something she doesn't want. Some of the behaviors I consider as challenging are when Tina sometimes becomes angry, screaming, disturbing and hurting herself by biting her hand or banging hear head against the wall which will be so stressful for me even if it is temporary.

And etagegn explained feeling of embarrassment when these difficult behavioral symptoms are shown by her daughter in front of people and then feeling of guilt for being embarrassed saying,

> Sometimes it is physically painful to interact with her if she is having a bad day and is attacking me or hurting me with her hand. I used to get so embarrassed when she does that in front of people and then I felt bad because it wasn't her fault. It is also painful to watch her struggle.

Tsehay also described being aware of her child's developmental disorder will be there permanently is stressful by itself saying,

> I had been so sad and desperate since I have Sintayehu to see that he has a disorder for a life time. When I got pregnant with Sintayehu I was eager to have someone by my side as a family who will support me at my elderly by getting higher education and having a good job but God gave me someone that I should support for the rest of my life instead (ሚፈ ስገኛለሁ ብዮ ተሚፈ ሰጠኝ). It's not that I hate my son; I love him more than anything but

> it hits me that the only family I have can't ever be independent and competent enough as his peers.

The discussion about how stressful and time consuming it is to manage a child with autism led the mothers talk about their difficulty to have time for themselves to do other things such as attending social events which developed the third theme under the second research question busy daily schedule and/or not having a time for oneself.

4.2.3. Busy Daily Schedule and/or not having a Time for Oneself

The mothers told the researcher how hard it is to have a child with autism because it needs huge amount of time to care for the child that makes it difficult to have time for themselves to do other things. For instance Roman said,

> I give a huge amount of my time to my son. I used to spend all my time at home. I don't get to go out with my friends instead they sometimes come home to cheer me. I usually not used to attend meetings, weddings and different social activities because I can't usually either leave my son at home or take him with me (ልጄን ይዤም ትቼም መሄድ ይከብደኛል). Generally I used to have no time at all to myself. I plan everything around my child.

And Hirut added

> I spend most of my time…… no, not most of my time all of my time with my child. I don't attend on many social events that I used to attend before I gave birth to Eyob because I can't be far from him and even if I went out I would be so anxious that something bad is going to happen to him where I left him. Sometimes I spend the whole day busy without a rest running around with Eyob to control him especially if he is having a bad day. It has been an evolutionary process because day-to-day life consists of management of Eyob's challenging behaviors.

Other mothers said that even if they want to have a time of their own leaving their children home they often worry about leaving their child alone with others for a long period of time due to their child's lack of ability to communicate, their difficulty finding and trusting reliable house maids or nannies to let their children stay with them and their fear that they may

be victimized or abused. Aster for instance spoke of feeling guilty on leaving her child alone with a house maid,

> Sometimes I feel guilty spending time away from my child even if it is a must. I always worry to leave her with the housemaid at home before she entered the center that she stays at currently for a year. There is a lot of feeling of guilt leaving a child with a house maid that each mother has but it's more intense when you have a child with autism.

And Hirut further added, *"I no longer hire babysitters because I don't feel comfortable anymore about the kind of situation they generate with my son."*

After discussing the second research question which attempted examine the psychological challenges of these mothers in the individual interviews the researcher moved on to the questions under the next research question that endeavors to capture the experiences of the mothers on the social challenges they encounter while raising their children on the spectrum.

4.3. The Social Challenges of Having and Raising a Child with Autism

The third research question of this thesis paper was posed to answer the social challenges the participants in the study encountered while raising a child with autism spectrum disorder. The mothers spoke of several social challenges in accordance with their daily lives with their children on the spectrum including the effect on their family, negative reactions from the society and difficulty finding education, treatment options and support for their children.

4.3.1. Effect on Their Family

When the researcher and the participants discussed about the effect that raising a child with autism has on family, the findings were different in each cases. Some mothers referred specifically to how their child's developmental disability restricted their attention and time to their other children due to their child with autism needing more attention as an effect. For instance, Roman and Tsega explained that they give almost their full attention to their children

with autism giving less attention for their siblings in their everyday life even if they don't want to give more attention to one child than the other which led to conflict between them and their other children.

Other mothers reported some problems with their husbands as a result of their husband giving less attention for the child with special needs and/or due to exhaustion and conflicts on upbringing a child with autism as Hirut reported,

> It placed a negative effect on the family. For example my husband used to be tired at work because of the fact that we can't sleep at night before Eyob began to take his medication because he had difficulty sleeping and scream a lot at night. There were also lots of arguments about the child medicines and the costs between me and my husband.

And Aster said,

> Her father didn't really give attention to her and don't show care except financially since she was born. The full responsibility of taking care of her is on me and this makes me feel frustrated. Moreover, her sister and brother sometimes don't understand her. They get easily angry when she does something wrong as if she is a normal child and I feel sorrow deep down inside when they shout at her or beat her angrily which in turn picks a fight between me and them.

After discussing the impact of raising a child on the spectrum on their family mothers mentioned how the society views their children's developmental disorder in many of the interviews which contributed to the occurrence of another theme that is reactions of the community.

4.3.2. Reactions of the Community

The findings under this theme were two types as the participants in this study differed in reporting the types of attitudes and comments they get from the society about their children. Half the mothers reported sympathy and love from neighbors and community members towards their children such as Roman and Tsehay,

> I didn't get any offensive or negative comment or attitude from the society about my son. People around me know my son's condition even if they don't have a detailed knowledge about the developmental disorder. They show sympathy for my son and also try to encourage me on all the things I am doing. (Roman)

> People that know me know and love my son so much and show countless sympathy towards him. But I can feel people's eyes on us, judging us or showing sympathy. I mean everybody stare at us and stare at him. (Tsehay)

However, the other half of participants talked about how lack of understanding from the public gave them a hard time and how being negatively evaluated by people around made them feel judged over time. For instance Tsega clarified,

> The general public in the country, anything that is not normal whether it is autism or mental retardation they can't well understand. I did feel on my own because nobody seems to understood why he display such unique behaviors and what I am going through because he doesn't look disabled. I get really angry with people when they try to tell me what I should be doing with my son to make him behave well.

And Hirut enhanced,

> Neighbors didn't really understand his problem until recently. They thought he was just a spoiled boy not knowing that its autism that is making him act that way. For example: - he used to hit the gate to our house hard with a stone which makes a huge noise the whole day and he would be so angry, screams and cry if we try to stop him, all the neighbors used to come to complain and to tell me how to make him a calm and unspoiled child.

Aster further spoke of how people lack of understanding makes her daughter stigmatized around their neighbor saying,

> There were some neighbors that didn't want their children to play with her as if her condition is a disease that can be transmitted to their children. For example, one day Tina was standing outside of our compound watching other kids playing, then one of the kids called her to play with them and I heard one of the kid's mother saying 'don't call her she is a sick person' which was really sad for me knowing my daughter won't be able to participate in the common plays that every kid plays.

Other than the society's lack of understanding which made the mothers felt alone and their children stigmatized nearly all of the mothers similarly mentioned how difficult it was and

still is to find education and other support for their children to socialize them with their peers which led to the manifestation of the next theme difficulty finding education, treatment and support for their child.

4.3.3. Difficulty Finding Education, Treatment and Support for Their Child

Many mothers stated challenges related to finding a school or appropriate school for their children and difficulty to find treatment options other than medications commonly prescribed to their children following their diagnosis. For example, Roman talked about having trouble finding appropriate or accepting school and different treatment options from other medical organizations until a year ago due to the autism center she knew was full that obligated her to be registered on the waiting list because there were no private schools that was willing and that has the capacity to give education for children with autism.

And Tsehay talked about how it's very difficult for her to find any treatment or education for her son until now because the nearby governmental school has no classes for people with autism and the other governmental schools said it will be difficult for her son to stay the whole day there. Tsehay further said that no one has ever offered help at all except for some of the people she mentioned and the drugs that were given to her son at the diagnosis clinic which she take from monthly where the researcher found her.

Aster also told the researcher that she wants her daughter to continue in the nearby private school she has been attending for three years, but due to the additional cost and their refusal to let her daughter continue there because she is getting older without proceeding from class to class, it is getting harder for her daughter to be there for the future. Aster further added that she wonders if the government has ever thought about autistic kids' medical institution or governmental schools for them.

In relation to the challenge the mothers face finding education and other supports for their children some of them were even obligated to quit their jobs to manage their children. For example, Roman said she was not able to work at all until her child was six years old because she couldn't leave him and there were no school that accepted him. Aster further said,

> I was obligated to leave my work for four years to train my daughter and to take her to holy water and monasteries for a period of times. After she showed some changes as she gets older and after she got easier to handle than before I turned back to work but I'm always worried about her while I'm at work.

Despite the many challenges the mothers spoke of all of them identified coping strategies that worked for them and they adapted to the experience of having a child with autism over time which are discussed with the researcher under the fourth research question.

4.4. The Effective Coping Mechanisms Used by the Mothers of Children with Autism to Deal With the Often Demands that Autism Entails

Finally, the fourth research question intended to answer what type of coping mechanisms that were effective to the mothers while dealing with the difficulties they encounter raising a child with autism. Four themes emerged as significant from the mothers' responses but religion occurred to be the most prominent one.

4.4.1. Religion

The most used coping mechanism by being reported in all the mothers' interviews was religion. Some of the mothers stated that they engaged in spiritual beliefs and used spiritual healing methods such as holy water and prayer to their children and themselves to decrease the developmental problems of their children and to cope with the challenges they faced. For example Roman said,

> I come from a strong academic background and even if I had expectations for my child I learned to let that go and appreciate what he is doing and the little things he is actually getting done after all my devastation. So I began to pray a lot and I used to drink holy water, let my son drink the holy water too. After wards God answered my prayer and my son's constipation has been cured, he was also able to sleep more than previously.

Other mothers coped through religion as a result of finding people that are going through the same things as them and that understands them while they are being involved in a Bible study and other church programs as Hirut indicated,

> My stress levels are lower when I participate in a Bible study on a regular basis and pray. I am trying to teach my son at home by getting advice from a good friend of mine who also has a child with autism that I met at the church. I have met more friends at the church who seem to have better understandings in children and tend not to be judgmental instead they can just act normal with you.

And Tsega added,

> I always go to church, read the bible and talk to my friends there when I am stressed about my son or when I got exhausted and I come back peacefully and calmly. I'm also taking my son to church to have a prayer for him together with other people until now. I think the church is excellent because people there understand his behavior and the spiritual connection there helps to reduce the everyday struggle I face.

In accordance with religious coping some of the mothers mentioned that it was important to be informed and be educated about the facts regarding their child's condition which led to the existence of another theme under the fourth research question which is educating oneself about autism.

4.4.2. Educating Oneself about Autism

In order to cope with having a child with ASD and its associated behavioral or emotional problems many mothers reported that it was important to be educated, know the facts and gather available information regarding their child's condition. Some of the mothers told the researcher that the current knowledge they acquire by reading from the internet helped a lot when it comes

to managing their children's behaviors and teaching them important skills. For instance Roman in detail stated,

> I read a lot about autism and educate myself about the many streams of the disorder like what should I do to train my son about necessary life skills for example to dress for himself, use toilet properly, eat appropriately and so on. My reading helped a lot when it comes to reveal the burden that I have to do everything for my son, it also helped me to know how to handle my son's difficult behaviors and what and how to plan for the future of my son and myself with God's will. The fact that that I read a lot about this issue gave me knowledge and that knowledge made me able to accept my sons developmental disorder in a way that it has already happened and I can't change it so I shouldn't blame anyone and think of all the negative things from it rather than strengthening myself and control many anxious moments and stressful events.

And Aster similarly said,

> The additional thing that helped me is reading about how to treat an autism child on the internet and from other available resources to acquire knowledge about the disorder and help my daughter because I think knowledge helps to relieve stress since it gives directions to deal with the situations that come up. As a parent I want to take advantage of anything that I could for the benefit of my child. So I am gathering bit information here and there.

Other mothers reported other people such as other parents of a child with autism as a great source of information and knowledge to educate themselves on many aspects of autism because they have similar experiences or concerns. For instance Hirut reported,

> The other thing that helped me is this friend that had a child with autism too that shares lots and lots of information about the disease with me because she is better than me in knowledge. By sharing information with her I am trying to teach my child different life skills in a way that is easy to him, I am trying to remove all the things and events that upsets him, for example, I am training him to sit calmly instead of pulling him to sit or to do things and so on. Further, knowing and talking to this friend of mine has helped me so much in a way that I knew I wasn't alone and there are many other mothers in my situation, I knew my son's condition can be improved and my worry has a bit lessened.

In relation to talking about other parents as a source of information the mothers and the researcher come to discuss about the kinds of used social supports by the mothers and to what extent they helped.

4.4.3. Social Support

The participants spoke of different kinds of social supports that helped them reduce the psychological and social challenges they faced related to their children on the spectrum. Two of the mothers (Roman and Etagegn) find the support of the organization their children stays at as an important social support.

> The center that my son joined 3 years ago helped me a lot to deal with the challenges I mentioned. The fact that my son stays there for 7 hours a day helped me to get back to work, helped me to have some time to myself like going out with my friends and attend social events. I can say my child has found education at the center since he is being trained in different skills. The classrooms are excellent. I believe it teaches him appropriate behavior to situations and appropriate social interaction skills. I also found other mothers the same as me at the center while picking my son up or while different parent meetings. (Roman)

For Hirut the social support from other parents of a child with autism and support of her religious community was helpful in many ways. And Tsega mentioned her husband and mother-in-law as a social support that had been very supportive and helpful in raising her child saying,

> I did not know how I would manage this entire thing without my husband. We have become organized in the distribution of responsibilities as to who does what. I have good family supports with my mother-in-law who is capable of keeping him. If my mother in low is available, he is there with her and I have that support.

The mothers reported having a social support weather it is from their spouse, extended family and/or an organization was the one contributor for them to have a sense of appreciating the smallest steps forward that their children made, accept, normalize their children's autism and

plan ahead in doing everything for their child in order to provide the best for their children which emerged the last theme under the last research question.

4.4.4. Acceptance and Appreciating any Progress the Child Makes

Some of the mothers described a process of accepting and adapting to their child's autism in order to provide the best life they can for their child and this acceptance and normalization is an important part of these parents' experiences that facilitated their ability to cope with their child's autism and to appreciate progress in even the smallest steps forward that their child made, which brought them great joy. For instance, Aster told me that even if her daughter is not necessarily developing at the rate of other children are she is doing things easier that led Aster able to cope with things better and get satisfied with every little progress that her daughter is making because it's like another difficulty that she's overcome.

Other participants such as Etagegn demonstrated that it is effective to keep set routines and a planned schedule because the busy schedule and the tendency of their child with autism to have tantrums when routines were altered required continual planning.

Finally, these participants were asked to give advice to other mothers who are raising a child with autism. All the six participants said they would advise other mothers that they are not alone so not to lose hope and they stressed the importance of believing in God, praying by having faith to deal with the challenging aspects that come with raising a child with autism. For instance Etagegn told the researcher that other parents should do the best they can and take pride in how well they do for their kids by remembering that their children needs them and recognizes that they are the person that they can count on even if they can't tell.

And Aster said that other mothers should be curious if they see something different about their child because if their children's case can be known early they can show progresses by being treated as they are the nearest family for their children with autism that they can depend on.

Roman further gave a touching advice saying,

> I advise similar mothers not to lose hope and think that they are not the only one with a child with autism. I believe there are many ways to improve their child's conditions and to also deal with all the stressful issues in raising a child with autism so they should give that a try because you feel you're coping if you think I've tried that. Trying gives a sense of being in control and being more in charge of your life. In having a child with autism some things are so much out of your control but any little things that you can do to you child and any little things your child acquires means a lot that motivates you to control your life again.

4.5. Interrelation of Themes

Most the themes are interrelated; for instance, under the first research question feeling of loss, sorrow, shock as a reaction by the mothers was partially the result of mothers' lack of information and follow up during the diagnosis as the mothers explained those feelings they encountered after the diagnosis were more difficult due to the fact that they had no or little prior knowledge about autism and they were not fully informed at the time of diagnosis rather they were left alone to educate themselves about different aspects of the developmental disorder.

In addition, the mothers concern for their children's future was further aggravated due to their children's difficult behaviors that are hard to manage and this stress from managing a child with autism and their concern about their child's future led the mothers to turn their faces to religion to be engaged in spiritual beliefs and use spiritual healing methods such as holy water and prayer to decrease the developmental problems and difficult behaviors of their children that makes them stressed while managing them and in turn this would make them less anxious about their children's future .

Moreover, the difficulty finding education and support for their child lead the mothers to having busy daily schedule and/or not having a time for oneself and obligated the mothers to cope with educating themselves about autism as it was important to be educated, know the facts and gather available information regarding their child's condition to better manage their children's difficult behaviors and home teach their children important skills that they could acquire at school.

The mothers also were obligated to find possible social support as a result of difficulty finding education, treatment and support for their children as they reported having a social support weather it is from their spouse, extended family and/or an organization was a huge help for them to have a little time for themselves and one contributor for them to have a sense of appreciating the smallest steps forward that their children made, accept and normalize their children's autism by planning ahead with the presence of people that care.

To summarize the researcher also noticed a relation between the participants' response and their educational level as the relatively more educated participants tend to use the coping mechanism of educating one self and obtaining different information more than the less educated ones, this could be due to they know more about the power and usefulness of knowledge on their coping process and to be able to provide their children with important skills at home and due to the fact that it's easy for them to get rich information from different sources and educate themselves. Further, the more educated mothers got more logical and detailed conversation with the researcher while the less educated ones gave generalized and less detailed answers. Also the more educated mothers' discussions were coherent and directly related to the question that was posed by the researcher.

Chapter Five

Discussion

This chapter discusses the findings presented in the previous chapter on the perspectives of birth mothers on the psychological and social challenges of raising a child with autism and the coping mechanisms they used to deal with those challenges. The four research questions will guide the discussion as headings and findings derived from the respondents' interviews under each research questions will be discussed in terms of how they relate to previous published researches. Moreover, the findings under each research questions will also be discussed in relation the theoretical framework which is Bronfenbrnner's Ecological Theory (1979), within which this study was supported by previously in chapter two.

Therefore, the study findings on the first research question which was posed to answer the experience of mothers on the diagnosis process of their children on autism spectrum disorder will be presented first by including the four emerged themes under this research question. Then the findings on the second research question which examined the psychological challenges the participants faced in relation to raising a child with autism will follow consisting the three most prominent themes that were formed in chapter four.

The study results under the third research question which assessed the social challenges those mothers faced in their daily lives will then be discussed considering the three themes that occurred as significant during the analysis. Finally, the discussion of the results under the fourth research question that looked at the coping mechanisms that were used by the mothers and that are found to be effective in helping them deal with the challenges they reported as a parent of children on the spectrum will finally follow.

5.1.The Major Reactions and Experiences of Mothers During the Time of Their Children's Diagnosis

As indicated previously the first research question attempted to answer the major experiences of the mothers of children with autism during and after the diagnosis time. The student researcher asked questions such as what the mothers first notice and/or suspect something different in their child about his/her development that led them to make the diagnosis, how they felt, respond and/or react when they learned their child is diagnosed with autism, if there was any support or if they were provided with necessary information during the diagnosis process, how much they knew about autism before the diagnosis, if they have changed or if their parenting ways has changed after they learned about their children's autism and what they personally believe to be the cause of their children's developmental problem.

In accordance to how the mothers felt, respond and/or react when they learned their child has autism, it was found that all the participant mothers similarly displayed a range of emotions following the diagnosis including despair, sadness, shock, confusion and/or feelings of loss that emerged the first theme Sorrow, shock and feeling of loss as a reaction by the mothers.

This finding is consistent with many studies across the world that found feelings of despair, sadness, or being overwhelmed by parents upon first hearing of their children's diagnosis and a period of bereavement associated with those feelings including (Paul, 2001; Altiere, 2006; Bayat, 2007; McCabe, 2008; Kirsten, 2008; Lori, 2008; Maggie, 2010; Ashley, 2012; Joachim and Robert, 2012; Durban and Rodriguez, 2012; Angela, 2013 and Lindsey & Roberta, 2013).

After conversing the mothers' reactions the student researcher wanted to know how much was the mothers' level of knowledge about autism before they learned about their children's

condition and many of the mothers reported that they knew very little before they made the diagnosis for their children and this lack of knowledge was one contributor for the encountered difficulties including feeling of loss of a child and denial while learning that their children has a developmental problem.

Similar to this study (Lindsey and Roberta, 2013; Ashely, 2012; Maggie , 2010; Anthony, 2009 and Murphy and Tienery, 2007) found parents were extremely limited in their understanding of the disorder and this limited prior to their child's diagnosis and this lack of knowledge by parents led to initial reactions of denial, fear, and shock to take longer to be recovered.

The participants also indicated that they were on their own to educate themselves about different aspects of the developmental disorder including intervention options because they were not fully empowered with information about autism by the professionals at the clinic. Further, all the participants reported that they received very little or no support from the professionals at the clinic before and after the time of the diagnosis, and reported a lack of useful information, direction or guidance.

This is in line with studies of (Murphy and Tienery, 2007; Anthony, 2009; Gona, Mung'ala-Odera, Newton, and Hartley, 2010 and Joachim and Robert, 2012) that found parents being dissatisfied with the quantity and quality of information available to them following the diagnosis and the service offered to parents during the diagnosis of their children by professionals was inadequate, and sometimes manifested insensitivity.

Bello-Mojeed, Bakare and Munir (2013), consistently argued that this lack of information and unsatisfactory service during the diagnosis of children with autism may be due to lack of or inadequate knowledge about developmental disorders of primary health care workers in Africa

because they do not routinely undergo training in developmental disorders such as Autism spectrum disorder.

Consequently the mothers demonstrated that on their way of educating themselves about autism due to the lack of information and guidance after they learnt their children's conditions at the clinic they begun to be changed positively as a person and as a parent. Most of mothers mentioned that having a child with autism changed them positively in which they become tolerant, patient, being less judgmental and sympathetic for other people and appreciative of little things over life. In some cases participants also described that their experiences with their autistic child had increased the level of closeness on their family which emerged the theme being personally changed as a result of children's diagnosis.

This is similar with (Bayat, 2007; Kirsten, 2008; Maggie, 2010 and Angela, 2013) where all found parents' increased level of tolerance, patience, improved assertiveness, being less judgmental of other people, redefining their priorities in life, or taking joy in the small victories of everyday life and strengthened relationships between family members working together as a result of having and raising a child with autism.

Finally the researcher wanted to know the mothers' hypothetical believes about the cause of their children's developmental disorder before moving to discuss questions under the next research question. Nearly all the mothers thought as they have been chosen by God to have a special needs child as their explanation for the cause of their children's special needs because they didn't do anything wrong during their pregnancy time, during and after birth that can be considered as a threat to the fetus or the infant except one mother that differently reported her child's disorder could be a result of her age being late to have a child.

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 intellectual disability to God.

However, this finding contradicts with the western studies such as (Russell & Norwich's, 2011) from the United Kingdom, (Altiere's, 2006) in United States, (Shaked & Bilu's, 2006) in Israel where the majority of parents agreed with the scientific findings that to this date no one has discovered an exact cause of autism but either genetic or environmental causes including labor complications, problematic infant immunization, genetic inheritance, viral infection during pregnancy, head trauma and organic defect in the brain as causes for their children's developmental disability.

From the student researcher's point of view this could be due to the fact that the western countries have sufficient services with trained professionals and quality child care facilities that can provide parents with sufficient information about the causes, behavioral manifestations, and intervention options of autism.

This finding also contrasts with the many African studies such as Anthony's (2009), that provided a look at the understanding of autism in Ghana, mothers were to blame by themselves or others for their child's developmental disorder either by not providing quality prenatal care, a failed abortion attempt involving ingestion of tonics and experiencing some illness or accident during the course of their pregnancy as the cause for ASD.

Joachim and Robert's (2012), study is also another African study from Zambia that contradicts with the current finding of this study by stating that several families reported the cause of their child's ASD was witchcraft or gap of traditional cultural taboos. Gona, Mung'ala-Odera, Newton, and Hartley (2010), from Kenya also stated that parents reported the disability of their children is associated with evil spirits, punishment from God or witchcraft.

With regard to the theoretical framework in supporting the first research question Ecological theory has implications for an understanding of the nature of autism and the manner to structure autism services including the process of diagnosis by stating human development, including that of persons with autism occurs in the context of multiple dynamic transactional systems, with both immediate and more remote environments affecting the individual on the spectrum.

The diagnostic services, therefore, should be tailored to sort out, understand, construct, and control the transactions among those environments for the ultimate benefit of children with autism and their families. According to ecological theory professionals that make the diagnosis process should consider the parents' feelings and provide them enough information and support to reduce their difficult reaction of hearing the results, to increase their acceptance of the disorder and to make them take action quickly. To do so, based on the results of the assessments during the diagnosis, referrals should be made to early intervention services, school districts, other medical service providers and parent supporting organizations as appropriate to initiate services between the child and the multiple ecological levels that affect the child.

5.2.The Psychological Challenges Faced by Mothers Raising a Child Diagnosed with Autism

The mothers spoke of several psychological challenges they endure when raising their children on the discussions with the student researcher about the questions under the second research question of the study. The student researcher asked questions to capture if the mothers have faced any challenge that made them worry, fear or be anxious on raising a child with autism, if they experienced any kind of stressors related to having and raising a child on the

spectrum and what the difficult and challenging thing in their everyday lives of managing an autistic child.

Thus, permanent worry about their children's future occurred to be the main psychological challenge as who would care for their children when they no longer can be there for them and what the future would hold for their children which emerged the first theme under the second research question that is Concern about child's future.

This is consistent with other similar studies such as (Paul, 2001; Gray, 2002; Murphy and Tierney, 2007; Bayat, 2007; Kristen, 2008 and Angela, 2013) findings that stated the failure of children with autism to recover, the child's level of independence and being a burden later in life, and their inability to maintain relationships as well as what would happen to their child if they themselves became ill and could no longer take care of them as a great source of psychological distress for parents particularly mothers of children with autism.

Other studies also established that mothers appear to be the most affected to experience conflicting emotions over the permanency of their child's condition such as (Aadil et.al, 2014; Kourkoutas et.al, 2012; Michelle, 2007 and Maggie, 2010).

While talking about the mothers concern for their children's future they noted that it was further aggravated due to their children's difficult behaviors that are hard to manage which contributed to the second theme under this research question that is stress from managing a child with autism.

It has been found that mothers' face higher level of strain related directly to their children's behavioral manifestations in managing child with autism which in some cases resulted into parents getting frustrated and exhausted. Further the respondents reported that they felt

continuous sorrow being aware of their children's developmental disorder will be there permanently.

This is similar with several studies such as (Gray, 2002) that found the parents who were the most distressed were those whose children were aggressive and/or severely obsessive and (Abbeduto et.al's, 2004) finding that the most consistent predictor of maternal stress was their children's behavioral difficulties.

Further, several studies such as (Boyd, 2002; Montes and Halterman, 2007; Susan, 2008; Kirsten, 2008 ; Bello- Mojeed et al, 2013; Lindsey and Roberta, 2013; Lori 2008; Aadil et.al, 2014) stated parents reported stress due to the fact that their child was much harder to care for than most children his or her age and reported behavioral issues, tantrums, screaming, and physical violence toward themselves and others associated with the disorder made parents of children with autism face extreme challenges daily in dealing with the behavioral problems associated with the disorder.

In relation to the discussion about how the behavioral problems associated with autism are difficult to manage the mothers also declared it is also time consuming which make it difficult to have time for themselves to do other things such as attending social events which developed the third theme under the second research question busy daily schedule and/or not having a time for oneself. They also reported being busy with everyday routines and not being able to find reliable house maids or nannies for their children.

This is similar with many findings such as (Meirsschaut, Roeyers and Warreyn, 2011) that reported there was little time left for personal activities or outings by mothers that care for autistic children. Gona, Mung'ala-Odera, Newton, and Hartley (2010), also described even if

mothers needed time to attend to community obligations most of their time was spent on the child with a disability.

Moreover, Aadil et.al, (2014) similarly found feelings of loss of control of personal life by mothers as another important factor associated with parental stress in families of children with autism. And Angela, (2013) found mothers having busy daily living that included managing their child's challenging behaviors, acting as their child's therapist or teacher which make it hard for them to have time and think about their own needs.

The mothers in the current study as well reported felling of guilt related to leaving their child alone with others due to their child's lack of ability to communicate and the fear they may be victimized or abused as another psychological challenge which is consistent with (Kirsten's, 2008) findings that stated guilt was found to be experienced by parents of children on the spectrum in relation to spending time away from their child.

The findings and discussions under the second research questions are supported by the theoretical framework since the ecological model takes into account the way in which the interactions between a child with an autism spectrum disorder and his/her parents produce reciprocal responses that shape the overall psychological wellbeing of both the parents and the child.

Furthermore the model states that the behavior of a child will have an effect on the behavior of parents, friends, child care staff, etc. and their behaviors will affect the child, therefore, a child displaying a disruptive or aggressive behavior like a child with autism is more likely to elicit restrictive or aggressive parenting behavior which lead to feelings of guilt and stress, while a friendly and attentive child is more likely to evoke positive reactions from the parents and the environment as well (Sameroff and Fiese, 2000).

5.3. The Social Challenges of Having and Raising a Child With Autism

The third research question of this thesis paper was posed to answer the social challenges the participants in the study encountered while raising their children on the spectrum. The mothers spoke of several social challenges in accordance with their daily lives with their children on the spectrum including the effect on their family which is the first theme under the third research question.

When the researcher and the participants discussed about the effect that raising a child with autism has on family, the findings were different in each cases. Some mothers referred specifically to how their child's developmental disability restricted their attention and time to their other children due to their child with autism needing more attention as an effect.

This is similar with (Ashley, 2012) that found raising a child on the spectrum impacted the relationship of parents with their other children due to the children with autism needing more attention and (Meirsschaut, Roeyers and Warreyn's, 2011) that concluded having a child with autism impaired family functioning in several ways including giving more attention to the special needs child which reduced the tendency of families to do normal or spontaneous family activities.

The other finding under this theme was the participants experiencing some problems with their spouses as a result of their husband giving less attention for the child with special needs and/or due to exhaustion and conflicts on upbringing a child with autism.

Consistent with this finding Joachim and Robert, (2012) reported marital conflicts emerged which included separations and fighting. All mothers in their study said they were greatly affected due to conflicts with their spouses related to the extreme demands on time and energy on parents and believed that their husbands have not fully accepted the child's condition.

Aadil et.al, (2014) also found that family members of children with autism are often perceived to experience adverse effects on marital adjustments, sibling relationships and daily family routines. And Maggie (2010) revealed participants felt some kind of an impact that are far from positive on their relationship with spouses due their child's diagnosis.

Other than discussing the impact of raising a child on the spectrum on their family the mothers also discoursed how the society views their children's developmental disorders which contributed to the occurrence of another theme that is reactions of the community.

The findings under this theme were two types as the participants in this study differed in reporting the types of attitudes and comments they get from the society about their children. Half the mothers reported sympathy and love from neighbors and community members towards their children that are similar with Murphy and Tienery, (2007) that reported sympathy was extended to the parents of children with autism from different members of society.

However, the other half of the parents talked about how lack of understanding from the public gave them a hard time and how being negatively evaluated by people around made them feel judged and stigmatized over time.

Other many studies are consistent with the current finding such as (Meirsschaut, Roeyers & Warreyn, 2011; Paul, 2001; Aadil et.al, 2014; Angela, 2013; Heather et.al, 2010; Joachim & Robert, 2012 and Lindsey and Roberta, 2013) that clarified participants complained about the lack of understanding of autism from the society and the unsympathetic comments from the general public made them feel being negatively evaluated, judged and isolated by people around them.

Moreover, (Bakare et.al, 2008; Bello-Mojeed, Bakare and Munir, 2013; African Network for the Prevention and Protection Against Child Abuse and Neglect (ANPPCAN), 2007) not only

found a very low level of knowledge and awareness about ASD among the general population, but a low to average level of understanding among health care workers in Nigeria which lead to negative attitude, avoidance, rejection, as well as negative comments.

Similarly, studies in Ethiopia such as (Lewis, 2009 and Getnet, 2013) found that attitudes towards people with developmental disability and their parents in Ethiopia are still characterized by stereotypes and prejudice, based on traditionally held views that link disability with immorality, punishment and curses.

In addition all of the mothers similarly mentioned how difficult it was to find education and other support for their children to socialize them with their peers. Many mothers also stated challenges related to finding treatment options other than medications commonly prescribed to children following their diagnosis that led to the appearance of the theme difficulty finding education, treatment and support for their children.

This finding shows the lack of access to educational opportunities and other child care facilities and intervention services in Ethiopia similar with UNICEF's (2009), estimation that that 98 percent of children with disabilities in Ethiopia have no access to school or vocational training. Further Lewis (2009), in his paper prepared for the Education for All Global Monitoring Report for united nations educational, scientific and cultural organization stated that even if Ethiopia have an estimated number of 1.7 to 3.4 million school-age children with special needs less than 1% of them have access to education in the country.

Lewis (2009), also attributed that disabled children do not go to school because teachers are not patient with them in the mainstream schools and fellow students do not understand their difficulties; while in the special school system there are too few schools, which are too far from home mostly confined to urban areas and have long waiting lists.

Studies from other African countries such as (Bakare & Munir, 2011a and Bello-Mojeed et al, 2011) from Nigeria; (Joachim and Robert, 2012) from Zambia; (Lara, 2007) from South Africa and (Anthony, 2009) from Ghana also support the current finding by illustrating access to quality intervention services, child care facilities, and education are far from satisfactory and African children with developmental disabilities are seriously underserved compared with western countries.

In relation to the challenge the mothers face finding education and other supports for their children some of them reported that they were even obligated to quit their jobs to manage their children. Ashely, (2012) similarly found participants' career was definitely impacted the most as they reported being fired from several jobs or having to give up their career to care for their child at home. Consistently, (McCabe, 2007 and Gray, 2002) described many families and mothers in particular, found themselves changing their work habits in order to better meet their child's needs in many cases by either not working at all or restricted their working hours and/or type of employment.

All the themes under the third research question are supported by the theoretical framework as it illustrate the impact of all the ecosystems or the immediate environments within which the child and the family he/she operate in. For instance, the first theme, the effect on family that is emerged as the mothers reported that how their child's developmental disability restricted their attention and time to their other children due to their child with autism needing more attention and some problems with their husbands as a result of their husband giving less attention for the child with special needs and/or due to exhaustion and conflicts on upbringing a child with autism clearly exemplify the impact of the microsystem as it's the immediate temporal

setting such as parents, siblings, extended family and school in which the child interacts with the environment.

The second theme reactions of the community can be related to macrosystem level of influence of the environment on individuals with autism that consists primarily of the societies' lack of understanding and negative comments which make the participants feel judged or criticized if their child exhibited symptoms while in public and a culture's overarching beliefs or values.

This again may speak to a larger cultural attitude toward people with disabilities as parents encounter most of the burdens and challenges that come from living with a child who has autism as his/her disruptive behaviors that may discourage the parents from going out in public as a family which reinforces the parents' isolation from resources and relationships in the mesosystem, and decreases the opportunities for a child with ASD to become familiar with new places and situations in the microsystem.

At the exosystem level, or the level of influence of more global factors such as the educational system, government programs, etc. the most notable exosystem impact mentioned was third theme as the mothers reported difficulty finding school or appropriate school for their child or their feelings that the schools their children had attended were not adequate in supporting the needs of children with autism.

5.4. The Effective Coping Mechanisms used by the Mothers of Children with Autism to deal with the often Demands that Autism Entails

Finally, the fourth research question intended to answer what type of coping mechanisms were effective to the mothers while dealing with the difficulties they encounter raising a child with autism by containing questions such as what would be the ideal way for the mothers to cope

with the stress they reported in relation to their children with autism, the strategies they utilize to overcome the mentioned other challenges and if they got any support from their spouse, extended family, friends and/or organizations.

Thus, the most used coping mechanism by being reported in all the mothers' interviews was religion which contributes to the development of the first theme under the fourth research question which is religious coping. Some of the mothers stated that they engaged in spiritual beliefs and used spiritual healing methods such as holy water and prayer to their children and themselves to decrease the developmental problems of their children and to decrease the stress of themselves that came from managing their children. Other mothers coped through religion as a result of finding people that are going through the same things as them and that understands them while they are being involved in a Bible study and other church programs.

The finding is consistent with (Gray, 2006) that reported parents cited religion as a coping strategy remained the same over time from his initial study (Gray, 1994), the parents in this study may have found it more important to acknowledge the permanence of their child's disability and find a way of thinking about it that will put it into a meaningful perspective through religion. Accordingly, (Gona, Mung'ala-Odera, Newton, and Hartley, 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.

It was also constant with (Durban and Rodriguez, 2012; Latafa, 2014; Bayat, 2007; Pauline, 2014 and Tiffany, 2010) that testified parents were able to find solace in religion and being involved in a Bible study because it can give them strength to continue to go on with their

lives despite the challenges they face with the extra burden of taking care of the child on the spectrum and as in their case the church members offered emotional support.

In accordance with religion in order to cope with having a child with ASD and its associated behavioral problems many mothers secondly reflected that it was important to be informed and educated about the facts regarding their child's condition which led to the existence of another theme under the fourth research question which is educating oneself about autism.

Some of the mothers told the researcher that the current knowledge they acquire by reading from the internet and books helped a lot when it comes to managing their children's behaviors and teaching them important skills. Other mothers reported other people such as other parents of a child with autism as a great source of information and knowledge to educate themselves on many aspects of autism because they have similar experiences.

Comparable with the current study (Murphy and Tienery, 2007) found that to cope with associated problems of having a child with an autism parents valued the information from a variety of sources including internet and other parents of children with ASD; and (Heather et.al, 2010) stated that participants in their study found their own knowledge as the key to their being a successful advocate for their children.

Moreover, (Hossein et.al, 2013 and Kirsten, 2008) both similarly stated that mothers education significantly can predict the level of mother empowerment and participants acknowledged the value of learning from other parents as part of being able to get on with things.

In relation to talking about other parents as a source of information the mothers and the researcher come to discuss about the kinds of social support the participants got from spouses, family members, extended families and organizations and to what extent they helped. Some of

the mothers reported the support of the organization their children stays at as important because their children's stay there gave them relief from the busy days they had in managing them, made them able to turn back to work and give them the opportunity to meet other parents that also has children on the spectrum.

Similarly, Angela (2013), indicated that mothers reported finding the Jamaica Autism Support Association (JASA) to be a significant source of support to them in raising their child and to have the opportunity to connect with other parents raising a child on the spectrum through a support group or parent connection network at the center. 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.

Bayat (2007) further indicated the most useful source of formal support for the participant mothers seems to be parent support groups, where they feel free to discuss their concerns about rearing a child with autism without fear of being inspected.

Spousal support and support from extended families was also other types of social support found to be helpful in the current study similar with other studies such as (Heather et.al, 2010 and Boyd & Mancil, 2009) that indicated mothers found the participation of their spouses in the parenting and care coordination activities associated with raising a child with autism as critical.

Further, similar with this thesis (Pauline, 2014) reported Help from extended family support as another important coping mechanism; and (Latafa, 2014) indicated the extended family system in the traditional Arab cultures was found to significantly help individuals that care for children with autism deal with their life stressors.

The mothers finally reported having a social support weather it is from their spouse, extended family and/or an organization was the one contributor for them to have a sense of appreciating the smallest steps forward that their children made, accept, normalize their children's autism and plan ahead in order to provide the best for their children which emerged the last theme acceptance and appreciating any progress the child makes.

Similar with this finding a study by (Heather et.al, 2010) indicated mothers described that it is effective to set routines and a plan schedules because the busy schedule and the tendency of their child to have outbursts or tantrums when routines were altered, required continual planning. (Kirsten's, 2008) findings also stated participants described a process of accepting and adapting to their child's autism in order to provide the best life they can for their child and acceptance and normalization is an important part of these parents' experiences that facilitated their ability to cope with their child's autism.

Further, (Lindsey and Roberta, 2013 And Lori, 2008) indicated parents used acceptance as a way to positive personal development and empowering that directed them to concentrate on learning new skills such as research and advocacy.

The theoretical framework support the findings under the mentioned last research question since it postulates parenting successes occur when proper social supports are in place at the micro-, meso-, and macro-levels such as extended families in the micro system and support from other organizations in the meso system as reported by the participants in this study which is the third theme.

Moreover, many of the mothers' responses inform religion as a significant coping mechanism as the interaction between the mothers of children with autism as a microsystem and the community at churches as another microsystem had impacted the participants on dealing with

some of the challenges they reported previously which makes religious coping the mesosystem level of impact.

Generally, Ecological theory recognizes that community agencies and institutions should assist families of children with special needs, not just children alone. Further, churches, mosques, and other faith communities have a responsibility to help maintain positive relationships/connections in the community, particularly with those that have a child with autism because according to this study, families of children with autism who receive support from their faith community experience an increased ability to cope and lower levels of stress.

5.5. Conclusion

This study provided a preliminary look at the experience of mothers raising a child with ASD related to the diagnosis process, the psychological and social challenges as well as the effective coping mechanisms they used to deal with those difficulties in Addis Ababa Ethiopia.

In conclusion to the first research question, there is a clear evidence of the lack of mothers' knowledge and insufficient support and information during the diagnosis process resulted in mothers' confusion, sorrow and a sense of grief when learning about their children's autism. Perhaps the foremost difficulty that parents reported after the diagnosis was that there was no next step and there was little or no indication from the professionals as to where to go or what to do once the diagnosis was given, the majority of parents reported being left on their own.

In relation to the second research question raising a child with autism affected the mothers to be at risk for negative psychological outcomes including high levels of stress and anxiety because of their child's behavioral difficulty, knowing the permanence of the child's developmental disorder, worry over the child's future and lack of personal time from busy daily life.

In addition, in answering the third research question the present study confirmed that children with autism impacts mothers' personal and social life. As can be gleaned from the participants' interviews, having a child with autistic disorder in a family poses unique and long-term challenges causing problems on the mothers' relationships with spouses and affects siblings as the mothers give more attention to their child with autism, can change how parents determine where and when they are able to go, affect their friendships, change their social connectedness with the community, and affect career decisions.

Further the mothers raised lack of awareness that led to negative comments from community members which made them feel stigmatized and lack of appropriate facilities for them and their children such as educational and interventional services as a social challenge under the third research question.

However, the mothers also reported a number of positive impacts of raising a child on the spectrum aside with the challenges they faced including their personal positive changes such as redefining priorities in life, increased tolerance, patience, and being less judgmental.

Thus, despite the challenges and difficulties they encounter as mothers of children with special needs the current study established that the mothers used coping mechanisms that they perceived effective to decrease or deal with those challenges under the fourth research question. They reported religious coping either by praying, involving in church programs and/or bible studies or by taking their children to monasteries and holy water as a significant coping method. Also information and knowledge as it is important to be educated and know the facts and information regarding their child's condition to better manage their children for accepting their children's developmental disorder by planning ahead on activities that should be done for their child in order to provide the best was listed as another way to deal with their situation. Further,

social support from spouses, family members, extended families and organizations was another reported coping mechanism.

Finally, although raising a child on the spectrum appears to be a long and possibly challenging journey for the mothers, they reported that they would advise other mothers who has a child diagnosed on the spectrum that it is important to believe in God and have hope, pray and to participate in religious activities, to educate themselves on their children's developmental disorder and to try whatever they can to help their children. Finally, most mothers identified areas where systematic improvements would be helpful to their families, including greater awareness of autism in the community, greater governmental supports as well as educational and treatment services.

5.6. Recommendations

The current study found that the participants lack knowledge at the time they made the diagnosis for their children which contributed for the encountered difficulties including feeling of loss of a child and denial while learning that their children has a developmental problem. Further, they indicated that they were on their own to educate themselves about different aspects of the developmental disorder including intervention options because they were not fully empowered with information about autism by the professionals at the clinic and they received very little or no support before and after the time of the diagnosis.

Therefore, support should be warranted in the time after initial diagnosis and follow up that contain valuable information in terms of coping strategies for parents, accessible services, and links for supports both within the community and professional organizations. The findings of this study also suggest that it can be important for clinicians to ensure that they ascertain parents

understanding of autism when giving a diagnosis and consider preparing parents for the possibility of autism as a diagnosis during the assessment period.

The student researcher recommended an information pack to be provided to parents at the time of the diagnosis through assessment centers that would contain a list of important phone numbers of professionals and service providers, things to do after receiving the diagnosis, information assembled from parents who have recently gone through it and a list of governmental and private special needs schools inclusive of children with autism.

The study also found that mothers of children on the spectrum encounter stress from managing their children because of their difficult behaviors and this challenge is further aggravated by the lack of educational and other support organizations that their children can stay for some hours a day.

Thus, a variety of services are needed from educational, health care and social policies that address the comprehensive burden of children with autism and their parents to weather governmental or private special needs schools and organizations that give therapeutic or intervention services and trainings on respite and/or home health care. It is important that federal policy makers understand and determine the most appropriate programs and equal access to education and intervention services to all individuals with autism and their family.

Declaration of the Rights of the Child indicate that the child by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection before as well as after birth. The long wait in the enrollment of a child at center who provided special support is against child right. In convention child right include right to education. Whether he is a child with special needs or normal right to education is basic. Hence

professionals need to advocate for the right of a child with autism in accessing every service as per their need.

Recommended interventions for children with autism should both remediate the characteristics of autism in the child to help parents address behavior management concerns in the home and community, and ways to cope with their children's behavioral difficulties and interventions that can alleviate the stress level of parents by providing access to sources of social support and parent training programs.

For instance parent support groups are an effective means of formal support for mothers of children with autism since participants confirmed that they would like to talk to others who have experience in autism either professionally or personally they need better access to support groups and professional help so they would be able to take advantage of speaking with others who had similar experiences.

Parent training programs may be another strategy for managing the challenges for these mothers of children with autism by educating them on topics of understanding the specifics of autism, typical and atypical growth and development of their children, strategies and techniques for teaching specific skills, managing challenging behaviors, and utilizing available types of educational approaches available to their child, sibling relationships and financial planning. These training programs could also serve an important support function for families by giving opportunities to meet other families of children with autism and might promote sharing of more effective coping strategies.

The other important finding of this study postulates that lack of understanding from the public gave mothers a hard time and being negatively evaluated by people around made them feel judged and stigmatized over time. Therefore, empathy and tolerance from all of us for those

who are special needs children and their families will help in improving the quality of life for those individuals. We need to make individuals with autism and their families feel welcome, being understood, accepted, and not judged.

To do so educating health care professionals, families, friends, and communities who lack the knowledge of autism should be top priority and academicians can play a role in educating the society by conducting more practical and ground breaking researches that can likely address misperceptions of developmental disabilities and children's special educational needs that can be applied in formulating different training programs and intervention services by moving beyond description to provide a deeper understanding.

The media can also play an important role in educating the community for the social acceptance of children with autism and their families because it is important that the general public also have access to positive images of families and people with autism so that people might gain a greater understanding of autism spectrum disorder and the challenges that families face over their lifetime through media and newspapers to be properly informed on the kind of support they can provide as a parent, sibling, family member, friend, neighbor or a member of the society. The large community at country level can be addressed through extensive media coverage about autism involving governmental and non-governmental bodies by preparation of pamphlet, blogging on newspaper and web sites can be used as an alternative approach in reaching the community.

Advocacy campaign should also be established to popularize knowledge and proper care about children with autism so that people are properly informed on the kind of support they can provide as a parent, sibling, family member, friend, neighbor or a member of the society.

Finally, support programs for children with autism and their parent in religious organizations should be formulated which can provide the needed opportunity for expressing their difficulties, sharing their experiences, solving their problems and more importantly, to develop a mutual help system beside the holy cure mechanisms they provide (i.e. holy water, prayer etc…) because religion and spiritual methods are found to be the major coping mechanism by the participants of this study. And partnership between these religious institutes, governmental institutions, hospitals, schools and other related agencies would be imperative to provide therapy facilities for children with autism at religious organizations beside the holy cure mechanisms.

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Appendix A

<u>የወላጆች የቃለ መጠይቅ ፎርም</u>

የወላጅ እድሜ _____

የወላጅ የትምህርት ደረጃ _____

የወላጅ ስራ _____

የልጅ እድሜ _____

የልጅ ፆታ _____

1. What were the major reactions and experiences of mothers during the time of their children's diagnosis?

1.1 **ስለልጅዎ የተለየ ነገር በመጀመርያ በእርስዎ ወይም በሌሎች የቤተሰቡ አባላት የተስተዋለው ምን እንደነበረ ቢያብራሩልኝ; በስንት ዓመቱ/ቷ;**

1.2 **ልጅዎን በመጀመሪያ ለባለሙያ ያሣዩት በስንት ዓመቱ/ቷ እንደሆነና የት በምን ዓይነት ባለሙያ እንዳሰመረመሩ ሊገልፁልኝ ይችላሉ;**

1.3 **ለመጀመሪያ ጊዜ ልጅዎ ኦቲዝም እንዳለበት/ባት ሲያውቁ ምን ነበር የተሰማዎት; ምላሾት ምን እንደነበር በደንብ ሊነግሩኝ ይችላሉ**

1.4 **በምርመራው ወቅት የተሰጥዎት ምክር ወይም ድጋፍ ነበር; ካለ ምን አይነት ምክር እና ድጋፍ እንደሆነ ቢገልፁልኝ**

1.5 **ከልጅዎ ምርመራ በፊት ስለ ኦቲዝም ምንነት ያውቁ ነበር; አሁንስ ምን ያህል ያውቃሉ**

1.6 **ከልጅዎ ምርመራ በኋላ የእርስዎ ቀጣይ እርምጃ ምን ነበር;**

1.7 **የልጅዎን የምርመራ ውጤት ካወቁ በኋላ እርስዎ ለልጅዎ ያሎት የወደፊት ግምት (ተስፋ) ምን ይመስላል;**

1.8 **በእርስዎ የግል አመለካከት የልጅዎ ኦቲስት መሆን ምክንያት ምን ይመስሎታል;**

1.9 **የልጅዎን ከኦቲዝም ጋር መኖር ካወቁ በኋላ የልጅ አስተዳደግ መንገዶት (ዘይቤዎች) ተቀይሯል ብለው ያስባሉ ከተቀየረ በምን አይነት መንገድ እንደሆነ ቢያብራሩልኝ**

1.10 **በአጠቃላይ ከልጅዎ ጋር ያለዎት የዕለት ተዕለት ህይወት ምን እንደሚመስል ሊነግሩኝ ይችላሉ?**

1.11 **የልጅዎ የኦቲዝም ምርመራ በእርስዎና በቤተሰብዎ ላይ ያሳደረው አዎንታዊ ወይም አሉታዊ ተጽዕኖ ነበር; የልጅዎ ኦቲስት መሆን ከታወቀ በኋላስ ሌሎች የቤተሰቡ አባላት የነበራቸው ስሜት እና ምላሽ ምን ይመስል ነበር;**

1.12 **ማህበረሰቡ ወይም በአካባቢዎ ያሉ ሰዎች ስለ ኦቲዝም ምን አይነት አመለካከት እና እውቀት አላቸው ብለው ያስባሉ; ምን አይነት አስተያየትስ አጋጥሞት ያውቃል;**

2. What are the psychological and social challenges faced by mothers raising a child diagnosed with Autism?

2.1 **ከኦቲዝም ጋር የሚኖርን ልጅ በሚያሳድጉበት ወቅት የገጠመዎት ስነ-ልቦናዊ ችግር ነበር፣ ከነበረ ስለሁንታው ቢያብራሩልኝ**

ለምሳሌ፡- እንቅልፍ ማጣት፣ መጨነቅ፣ መረበሽ፣ ውጥረት

2.2 **ከኦቲዝም ጋር የሚኖርን ልጅ በማሳደግ በኩል የገጠመዎት ማህበረሰባዊ ችግር ነበር; ካለ ምን አይነት ማህበረሰባዊ ችግር እንደገጠምዎት ቢያብራሩልኝ**

2.3 **ከልጅዎ ጋር ባሎት የዕለት ተዕለት ግንኙነትና ህይወት ውስጥ የሚስቸግሮት፣ የሚያሳስብዎት ወይም የሚያስጨንቆዎት ነገር ገጥሞት ያውቃል; ካወቀ ቢያብራሩልኝ**

2.4 **ልጅዎትን በመንከባከብ ምክንያት በስራዎት ላይ አሉታዊ ተፅዕኖ ገጥሞት ያውቃል;**

ለምሳሌ፡- ከስራዎት ላይ ከልጅዎ ተያያዥነት ባለው ጉዳይ አስቀድመው መውጣት፣ አርፍዶ መድረስ ወይም መቅረት አጋጥሞት ያውቃል;

2.5 **ከልጅዎ ጋር በተያያዘ መልኩ በቤተሰባዊ ህይወትዎ ላይ የተለየ አሉታዊ ተጽዕኖ ተፈጥሮ ያውቃል;**

ለምሳሌ፡- ከባለቤትዎ፣ ከልጆችዎ ወይም ከቅርብ ዘመዶች ጋር ባልዎት ግንኙነት ላይ

2.6 **ልጅዎን መቆጣጠር እና መንከባከብ በዕለት ተዕለት ህይወትዎ ላይ ተጽዕኖ አሳድሮ ያውቃል; ካወቀ ቢያብራሩልኝ**

2.7 **ለልጅዎ ተጨማሪ ህክምና፣ ትምህርት፣ እና ሌሎች አገልግሎት ማግኘት ምን ያህል ቀላል ወይም ከባድ እንደነበር ቢገልፁልኝ**

3. What are the coping mechanisms used by mothers of children with autism to deal with the often demands that autism entails?

3.1 **ልጅዎን በማሳደግ የዕለት ተዕለት ሂደት ውስጥ የሚገጥሞትን አለታዊ ተፅዕኖዎች ለመቀነስ የተጠቀሙት ዘዴ አለ; ካለ እነዛን ዘዴዎች ቢያብራሩልኝ**

3.2 **ልጅዎን በሚያሳድጉበት ወቅት የሚያጋጥሞትን አለታዊ ተፅዕኖዎች ለመቀነስ (ለማለፍ) የተጠቀሙአቸው ዘዴዎች ምን ያህል ጠቃሚ ሆነው አግኝተዋቸዋል; ምን ዓይነት መንገድስ የበለጠ ጠቃሚ ሆኖ አግኝተውታል;**

3.3 **ከተለያዩ ተቋሞች ድጋፍ አግኝተው ያውቃሉ; ካወቁ እነዛን ድጋፎች ምን ያህል ጠቃሚ ሆነው እንዳገኙ እና በምን መልኩ እንደሆነ ቢያብራሩልኝ;**

3.4 **ልጅዎት የትምህርት እድል አግኝቷል/አግኝታለች**

- ካገኘ/ች ምን አይነት ት/ቤት ውስጥ

- ካገኘ/ች ምን ያህል የልጅዎን ት/ቤት መዋል ጠቃሚ ሆኖ አግኝተውታል

- ልጅዎ የትምህርት ዕድል ካላገኘ በምን ምክንያት እንደሆነ ሊገልፁልኝ ይችላሉ;

3.5 **ልጅዎ ተጨማሪ ህክምና አግኝተዋል**

- ካገኙ ምን አይነት ህክምና

- ካገኙ ህክምናውን ምን ያህል ጠቃሚ ሆኖ አግኝተውታል

- ካላገኙ በምን ምክንያት እንደሆነ ሊገልፁልኝ ይችላሉ

3.6 **ለሌሎች ከኦቲዚም ጋር የሚኖሩ ልጆችን ለሚያሳድጉ ወላጆች ምን ይመክራሉ;**

ይልተነጋገርንበት ግን የቀረ ጠቃሚ ነገር የሚሉት ካለ መጨመር ይችላሉ;

Appendix B

<u>የወላጆች የስምምነት ውል</u>

ሔለን ብርሃኔ እባላለሁ፡፡ በአዲስ አበባ ዩኒቨርስቲ የዲቨሎፕመንታል ሳይኮሎጂ የድህረ ምረቃ ተማሪ ነኝ፡፡ ይህ ቃለ መጠይቅ የሚደረግሎት ኦቲዝም ያለባቸውን ልጆች የሚያሳድጉ እናቶች የሚያጋጥሟቸውን ስነ-ልባናዊና ማህበራዊ አለታዊ ተጽዕኖዎችን እንዲሁም እነዚህን ተፅዕኖዎች ለማለፍ የሚጠቀሟቸውን የተለያዩ ዘዴዎች ለማጥናት ነው፡፡

ይህ ጥናት በጥናቱ ውስጥ ለሚሳተፉ ወላጆች፣ ለሌሎች ተመሳሳይ ወላጆች ጉዳዩ ለሚመለከታቸው የተለያዩ ተቋማት እና በአጠቃላይ ለማህበረሰቡ ስለ ኦቲዝም የተለያዩ መረጃዎችንና እውቀት ለማስጨበጥ እንዲሁም ኦቲዝም ያለባቸውን ልጆች ለሚያሳድጉ ወላጆችና ቤተሰቦች ስለ ኦቲዝም አመጣጥ፣ ስለምርመራው ሁኔታ፣ ቤተሰብ ላይ ስለሚያስከትላቸው አለታዊ ተፅዕኖዎች እና እነዚህን ተፅዕኖዎች ለማለፍ በተለያዩ ጥናቶች ስለተገኙ ውጤታማ ዘዴዎች የተሻለ እውቀት እንዲኖራቸው በማድረግ የተሻለ ቤተሰባዊ ግንኙነት እና የዕለት ተዕለት ህይወት እንዲኖቸው ለማድረግ ያግዛል፡፡

ስለሆነም በዚህ ጥናት ውስጥ ለመሳተፍና ከላይ የተገለፀውን የጥናቱን አላማ ተረድተው የቃለ መጠይቁን ለዚህ ጥናት ግብአት እንዲሆን በሙሉ ፈቃደኝነት ለመመለስ ፈቃደኛ በመሆነዎት ምስጋና እያቀረብኩ ቃለ መጠይቁን ለመመለስ የማይገደዱ መሆኑንና ከቃለ መጠይቁ በፊትም ሆነ መሃከል ላይ ቃለ መጠይቁን ለማቋረጥ ከፈለጉ ሙሉ በሙሉ የሚችሉ መሆኑን እንዲሁም ለመጠይቅዎት ጥያቄዎች ትክክል ወይም ትክክል ያልሆነ መልስ እንደሌለና የጥያቄዎቹ አላማ የእርስዎን ተመኩሮ ለማወቅ ብቻ መሆኑን ልገልጽ እወዳለሁ፡፡

ይህ ቃለ መጠይቅ ከአንድ ሰዓት እስከ አንድ ሰዓት ከሳላሳ ደቂቃ ሊፈጅ የሚችልና በቃለ መጠይቁ ወቅት አንዳንድ ግላዊ ወይም ምቾት የማይሰጡ ጥያቄዎች ሊኖሩ እንደሚችሉ በቅድሚያ እያሳወኩ ይህንን ጥናት እርስዎ በሚሰጡኝ መረጃ ላይ ተመርኩዤ ስጽፍ የእርስዎ ስም የማይጠቀስ መሆኑንና የሚነግሩኝ መረጃ በሙሉ በሚስጥር እንደሚያዝ እንዲሁም ከጥናቱ መጠናቀቅ በኋላ የሠጡኝ መረጃ ሙሉ በሙሉ እንደሚጠፋ አረጋግጥልዎታለው፡፡

የወላጅ ፊርማ _____ ቀን _____