



**Mothers' Voices: A Phenomenological Study on the Stress and Resilience of
Mothers Raising children with Autism**

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Mothers' Voices.....

Mothers' Voices: A Phenomenological study on the Stress and Resilience of Mothers

Raising Children with Autism

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Declaration

I, Ms. Rahel Fentahun, declare that this work entitled Mothers 'Voices: A Phenomenological Study on the Stress and Resilience of Mothers Raising Children with Autism is my own work and all the sources that I have used or quoted have been indicated and acknowledged by means of reference and this work has not been submitted before by any others at any institutions.

Rahel Fentahun

Signature _____

Place, Addis Ababa University, Ethiopia

Date of Submission- June 8 2020.

This thesis has been submitted for examination with my approval as University Advisor

Name – Fasil Nigusse (PhD)

Dedication

This thesis is dedicated to all those mothers parenting child with autism. Especially, I would like to dedicate this study to the mothers who took time off their busy schedules to talk to me. Their stories of resilience in face of many adversities encouraged me to keep on work on this research to project their voices.

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I would like to thank the ten mothers who participated in this study. I am indebted to them for sharing their deeply personal experiences with me. To them, I give my whole hearted gratitude.

I would like to dedicate my words for my beloved ones, my mother and father, for their prayer and support ,my brother ,for your support and unconditional love ,my sisters, aunties and brother-in –law ;you have always encouraged me to follow my dreams .You have always special place in my heart, God bless you abundantly .

Lastly, I say thank you to all who have helped me in diverse ways but whose names have not been captured here. The almighty God who knows all deeds richly bless you and replenish in many folds all that you have lost for my sake.

Acronyms and Abbreviations

ABA	Applied Behavioural Analysis
ADDM	Autism Developmental Disabilities Monitoring
ADDMN	Autism and Developmental Disability Monitoring Networking
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Observation and Schedule
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
CDC	Centre for Disease Control
FSRSPT	Family System, Resilience and Strength Perspective Theories
J-CCCARDD	Joy Centre for Children with Autism and Related Developmental Disorders
MRC	Medical Research Council
NDD	Neurodevelopment Disorder
NIDCD	National Institute of Deafness and other Communication Disorder
NUH	National University Hospital
US	United States

Abstract

Autism Spectrum Disorder is a complex neurological disorder which causes impairments in multiple areas of development including social interaction, communication and behavior. Although there are researches detailing the challenges, stresses, coping strategies and lived experiences faced by parents of children with autism, and the majority of this work did not involve the mothers stress and resilience in raising children with autism. Little known about mothers that; carry the bulk of parenting work in raising children with autism. Using qualitative phenomenological approach, this study sought to explore mothers' stress and resilience of having a child with autism. Bronfenbrenner's ecological systems theory and strength perspective were the guiding theoretical framework for this study .Ten mothers of children with autism were recruited through purposeful sampling .Semi structured interviews were conducted with mothers of children with autism. A thematic analysis was used to extract three major themes: (1) Major experiences of mothers during and after the diagnosis, (2) Causes of stress in mothers ' of children with autism, (3) Major Coping strategies used by the mothers' to strengthen their resilience against stress. .The thesis elucidated finding also have implications for policy maker, program developer, professionals and practitioners which recognition of mothers' meaning –making, stress, coping mechanism and resilience can influence policies, programs, strategies, child-based educational and therapeutic efforts. The finding can inform social workers, researchers, policy makers and program developers in facilitating strategies to mitigate these stressors; and help to establish a support to better supports mothers who have children with autism.

Keywords: Autism Spectrum Disorder, Stress, New Motherhood and Resilience

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1. CHAPTER ONE: INTRODUCTION

1.1 Background

A developmental disorder occurs when a child does not acquire normal developmental skills expected for their age. This affects their ability to learn, behave and socialize. Although a developmental disorder may be present from birth, it often does not become evident until a child is challenged with more complex social and cognitive tasks (American National University Hospital [NUH], 2004).

Autism is one of the most common developmental disabilities. American Psychological Association (2013) define Autism Spectrum Disorder is characterized by impairments in social communication, interaction and the presences of restricted and repetitive behaviors. According to National Institute of Deafness and other Communications Disorder [NIDCD] (2010) autism affects people of every race, ethnic group and socioeconomic. Source in presenting the prevalence are family, professional reports and children's evaluation records. A study by Autism and Developmental Disability Monitoring Networking showed the overall prevalence of 11.3 per 1000 (one in 88) from selected 14 ADDM sites of children aged 8 years old during 2008 (Center for Disease Control [CDC], 2012). As Sonya (2006), indicated ASD comprises the third most common developmental disability in which males are three four times 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 the age, with 51-91 % of these children exhibiting traits prior to age 3 (National Autism Center,2011:Tiffany,2010).

In addition, to date, a representative community based epidemiological study on prevalence, diagnosis, etiology and treatment of autism among African children is not available (Mashudat *et al.*, 2013). Moreover, 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.

According to Bakare et al (2009); Bakare& Munir (2011), Mojeed *et al.* (2011), late diagnosis has been found to characterized ASD and other Neurodevelopment Disorder (NDD) among African children in spite of early parental concerns about development. These studies suggested the possible factor includes poor awareness about the problems, cultural beliefs, and inadequate number of trained staffs, inadequate healthcare and intervention facilities.

Similarly, lack of scientific researches and documented data about autism made it impossible to find a statistical prevalence of autism in the case of Ethiopia. Different studies have presented their estimation. According to Nia Foundation (Autism in Ethiopia, para.1) the prevalence rate of autism is roughly the same as other regions of the world. In United States of America, one in every 115 children is diagnosed with autism and in Ethiopia population of more than 80 million a fair estimation at least 530,000 children suffer from autism and related disorder. An article by Getenet (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 with autistic cases. Moreover, there is lack of awareness on the existence of such kind of disorder.

Miodrag (2009) stated autism is a lifelong disorder affecting not only individuals but also members of the family as well. Parents in particular are greatly affected by

health and psychosocial status of their autistic children .In this regard several factors can be mentioned as reason for the stress that parents of children with ASD experienced .In particular, the availability of social support, severity of autism symptoms ,financial difficulty ,parents understanding and perception towards ASD, parents' anxiety and worries about their child's future, and religious belief are some key factors mentioned in the literature causing parental stress. Furthermore, child's unpredictable behavior, emotional problems are also explained as the main causes of stress in parents of children with ASD (Osborne and Reed ,2009;Ingersoll and Hambrick 2011;Rivard *et al.*,Sharpe and Baker 2011;Vohra *et al.*,2014;Zablotsky *et al.*,2014).

To this end, this study explored the stress and resilience of mothers of children with ASD by drawing upon Ecological System theory and Strength Perspective. The study conducted in Bright Autism Center and Nia Joy Foundation Autism and related developmental Disorder Center.

1.2 Statement of the Problem

Several studies worldwide looked into experiences of parents with autistic children especially the stress they are undergoing. Some of these studies particularly focused on some specific problem mothers of autistic children encountered.

Parenting children with autism spectrum disorder is more challenging than that of a child with typical development. Specifically, parenting child with autism can produce greater stress and sense of imbalance in the family system. Even though they have joy of being to hold and love their baby, their life is suddenly changing .This in turn produce feeling of grief, stress and confusion (Hartmann, 2012).

Alteriere (2006) showed that parents having child with ASD face many challenges associated with lack of understanding of the disorder. This is because parents tend to search for answers to their question during pre-diagnosis. Major factors related with parenting stress are social support, severity of autisms symptoms, financial difficulty and parents understanding towards autism.

Aadil *et al.* (2014) stated that mothers become closer to the child with autism while father works harder to earn money; consequently, fathers become irritated at the demands of mothers to interact with their children and mothers become frustrated at the lack of involvement of their partners. Besides, mothers appear to be the most affected and experience psychological distress .This is because mothers tend to have the first role in caring children with autism. They endure greater psychological pressure in balancing their autistic children with their normal life (Hosseini, Ayyub, Jail and Nafiseh, 2013).

Some researches indicated the cause of mothers' stress. Devis and Carter (2003) indicated that most consistent predictor of stress for mothers was child behavior such as their children social relatedness and their children regulatory problems (e.g., sleeping, eating and emotional regulation). Similarly, Pauline (2014) reported that autistic children mothers' interaction, with outside world and extended family, is difficult because the stigma they experience due to public display of their children behavior. Further, lack of awareness of autism in community aggravated maternal stress. Mothers experienced sense of isolation from their friends, family and the community (Angela, 2013).

From the researcher point of view, the issue of autism in Africa as well as in Ethiopia is not well known. According to World Health Organization (2011), limited supportive evidences in developing regions including Ethiopia regarding autism disorder

pose one of the major obstacles to establish efficient support programs for parents with autistic children. These evidences, if adequately available, could inform about the impacts of raising children with autism on their parents, adequacy of centers and trained staffs. A study conducted by Balfour (2007) found out parents of children with autism in South Africa are encountered various challenges due to the gaps in services and financial ability.

Further, Bello-Mojeeed *et al.*, (2013) indicated autism as serious and disabling neurodevelopment disorder but relatively little attention has been given to early identification in Sub-Saharan Africa. Likewise, Lewis (2009) stated that even if Ethiopia has 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. Aynalem (2014) showed most of families raising children with autism did not have prior knowledge about autism before the diagnosis process. It was also reported to be tiresome and long as most professionals in the medical settings were not responsive of autism with limited provision of psychosocial support. This exposed families to experience stress, shock and anxiety. Bezawit (2013) stated that psychological, social and economic challenges of parents of children with autism explained in relation with disrupted family integration, lack of awareness, inadequate social services, limited social support, controlled social life, influenced earning and expenses.

A number of studies identified coping strategies that parents employed to cope with their stressors of raising a child with autism. As Sivberg (2002) demonstrated that parents of autistic children develop flexibility, patience, problem solving and understanding the unique qualities of their autistic children. This opened a new path to

develop their parenting style with dignity and resilience. Correspondingly, parents used various coping mechanism such as consulting doctors, traditional coping mechanism, placing their children in autism center and using different support system (Soliyana, 2015). Many mothers of children with autism display characteristics of resilience and gaining strength in their new experience of raising autistic children (Durban *et.al.* 2012)

Despite the increasing understanding of what is like to be a parent and a mother of a child with autism, more research needs to be undertaken that strives to understand, make sense of and elicit the meaning of having autistic child from the perspective of a mother. This study uses a qualitative, phenomenological approach as a way of understanding the lived experiences of mothers. Furthermore, it is useful to include qualitative phenomenological component which provides the opportunity to know more about the lived experience of mothers of children with autism. Besides, this study attempted to brighten the resilience of mothers who are raising autistic children despite the adversity. Thus, the study answered the following research questions.

1.3 Research Question

1. What were the experiences of mothers of children with autism during and after the time of their children's diagnosis with autism?
2. What were the causes that bring stress in mothers of children with autism?
3. How did mothers' of children with autism develop coping strategies to strengthen their resilience against stress?

1.4 Research Objectives

General Objective: The aim of this research to examine the stress and resilience in mothers of children with autism.

Specific Objectives

1. To explain the experiences of the mothers of children with autism during and after the time of their children's diagnosis with autism.
2. To examine the causes that brings stress in mothers of children with autism.
3. To identify the coping strategies used by mothers to strengthen their resilience against stress.
4. 1.5 Operational Definitions
 - Autism Spectrum Disorder (ASD)-developmental disability related with impairment in social, communication and repetitive behaviors.
 - Mothers-individuals living, or primary care giver of a child diagnosed with autism.
 - Stress-feelings of worry faced by mothers of children with autism in living or caring a child diagnosed with autism.
 - Coping Mechanism-strategies develop by mothers of children with autism to manage their challenges and stresses.
 - Resilience-the ability in mothers of children with autism to endure their challenges and stresses while becoming stronger and more resourceful.

1.6 Significance of the Study

This study served as platform to some Ethiopian mothers of children with autism to share their experiences. Their experiences have implication for the mothers who have newly diagnosed child with autism. It gives an implication for social work profession role in assessing mothers' of children with autism stress to appropriate intervention services. To this end, the study also promote the social workers and other related professionals for

better assessment of the mothers stress and to seek resilience qualities for these vulnerable group of society. It is road map for policy maker and program developer to facilitate conducive policies and programs. Moreover, it helps as an allusion for governmental, nongovernmental and international organization to expand inclusive schools, autism centers and Applied Behavioral Analysis (ABA) services .Finally, this study has the potential to contribute in the field of education, disability and gender.

1.7 Scope of the Study

This study conducted in Bright and Nia foundation Joy Autism Center for children with autism. Bright Autism Center is the only center in Southern Nations and Nationalities Regional State. The center was established by mother of autistic child in 2016.It is located in Hawassa, around the area commonly called ‘Addisu Stadium’. Nia foundation Joy Center for children is the first autism center in Ethiopia. It is established by mother of an autistic child in 2002.It have a number of years of experience with greater number of beneficiaries. It is located in Addis Ababa, around the area commonly called “Sar bet”.

1.8 Delimitation of the Study

The study only recruited ten mothers of children with autism whose children are enrolled in Bright and Nia Foundation Joy Centers. The scope of this study was limited in Hawassa and Ethiopia. The quality of this study would have been enhanced by a larger geographical area used to solicit participants. Therefore, this study did not seek to generalize results to all mothers who raise children with autism in Ethiopia. Thus, it is recommended that further exploration be done in different service setting and geographic areas of Ethiopia.

1.9 Organization of the Paper

The study has been presented in six chapters. Chapter one introduces the study by providing background information on stress and resilience of mothers of children with autism. It discusses the study problem and outlines the research question and the objectives of the study. It includes the limitation of the study. It also further provides the significance of the study and its potential contribution to policy and practice.

Chapter two reviews relevant literatures relate to the topic. It presents theoretical perspectives that provide a framework for this study. In chapter three, the research methods detailing the choice of research design, study area, eligibility criteria, participants, data collection procedure and data collection instruments were discussed. This chapter outlines methods of data analysis and ethical consideration. Chapter four presents the major finding of the study. Chapter five provides a detailed discussion of the finding .Chapter six provides conclusions and social work implications

2. CHAPTER TWO: REVIEW OF RELATED LITERATURES

This study examined stress and resilience in mothers of children with autism. The purpose of this chapter is to provide some relevant literatures, researches, theories and discourses that conducted in the area of autism in relation with the perspective of mothers' of children with autism stress, different dimension of challenges, coping mechanism and resilience among children with autism.

2.1 General Overview of Autism

2.1.1 History and Definition of Autism

Autism was first described in early 1940s, and with developments in knowledge, the concept has been evolving ever since. The word autism was derived from the Greek word 'autos' 'mean self. The term was used to described behavior in 1943 by Leo Kanner, pioneered the application of psychiatry to psychological problems in children .In 1943, he published one of the first known account of autism, based on his case studies of 11 children referred to his clinic (Kanner, 1943).He recognized language problems; a typical use of non-verbal communication, such as eye gaze and gesture; narrowly restricted interests and a desire for sameness; and atypical reactions to sensory stimuli. The children's outward aloofness and isolation from the human world led him to coin the phrase "autistic loneness". The second autism pioneer was Hans Asperger, He described autism as behavior pattern very similar to Kanner's explanation, which he called 'autistic psychopathy' (Asperger, 1944). Though "psychopathy" he meant to a psychiatric disorder affecting the personality. Asperger highlighted important features in common with Kanner's case studies, yet the children he described seemed less disabled than Asperger's group, generally having fluent speech and vocabulary, even if they used it

oddly. They tended to talk at length about their favorite topic or interest. Rather than seeming unaware of the existence of others, their reactions to others appeared strange and antisocial.

Because of the striking difference among individuals with autism studies, researchers and practitioners define autism in various ways. The American Psychiatric Association's (APA, 2000) defines Autism Spectrum Disorder define as a group of disorders that include autistic disorders, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger's Disorder. The core deficits associated with an ASD are impairments in social interaction and communication, as well as the presence of unusual behaviors and/or interests. Autism Spectrum Disorder (ASD) occurs in all racial, socioeconomic and ethnic groups. It occurs four times more likely to occur in boys than girls. Algozzine *et al.* (2004) define Autism spectrum disorder is considered to be a severe disability secondary to the intense lifelong effects on the diagnosed individuals and their family. The American Psychiatric Association's (APA, 2013) considered autism as a group of disorders that include early infantile autism, childhood autism, Kanner's autism, high functioning autism, atypical autism and persuasive developmental disorder. Autism is considered to be lifelong, developmental condition that affects how individuals think, communicate and interact with the world around them.

2.1.2 Main Characteristics and Diagnosis Criteria

The feature of autism has many forms that affect people in a variety way and in varying degrees. The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (APA, 2000) classified the characteristics of autism in two to domains: the social communication and interaction domain and the repetitive behavior domain. The social

communication and interaction domain which includes (1) deficits in social emotional reciprocity, (2) deficits in nonverbal communicative behaviors and (3) deficits in developing and maintaining relationships. Besides, Roth *et al.* (2010) noticed the social characteristics of autistic people may not always value socializing as much others. Children in particular may react strangely to things like birthday parties and Christmas gatherings of family, finding comings, goings and surprise of presents overwhelming.

To date, there are no reliable biological markers for ASD. Diagnosis of ASD is based on behavioral observation, parental interview, developmental history and clinical impression (Dawson & Murice, 2009). The “golden standard” diagnostic tools often used in conjunction with the above mentioned are Autism Diagnostic Observation and Schedule (ADOS; Lord *et al.*, 2000) and the Autism Diagnostic Interview-Revised (ADI-R; Lord *et al.*, 2000). The ADOS is play based semi-structured assessment of communication, social interaction and play skills. It is designed to elicit social and communicative behaviors. There are four different modules to ADOS. The module utilized is determined by the developmental and language level of the individual being assessed. The ADI-R is a standardized caregiver interview used in differential diagnosis of ASDs.

2.1.3 Cause and Prevalence

Researches over the last half century have established autism as a neurodevelopment disorder. Early suggestions that ASDs might result from abnormal parenting have been abandoned in the face of overwhelming evidence for a biological basis and strong genetic component. Most researchers believe that ASDs have a variety of causes, perhaps all affecting the same brain systems, or impeding development through

disruption of different abilities necessary for social and communicative factors interact with genetic susceptibility is as yet unclear.

Autism is multi-factorial disorder in which many factors comes 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). Thus, the subsequent paragraphs consist some of the known genetic risk factors.

Johnson and Myers (2007) denoted that the cause has been intermediating because of genetic complexity and phenotypic variation in the developmental disorder which makes it a complex disorder that involves multiple genes. According to Centers for Disease Control and Prevention CDC (2009) indicated that genes are one of the more likely to develop ASD. Medical Research Council [MRC] (2001) supported this idea that ASDs are highly heritable, although the mechanisms are likely to be complex and involve the interaction of many genes. For example, the probability of both twins having an ASD is high (60%) if they are identical (monozygotic) whereas if they are non –identical (dizygotic) the probability is very small.

Furthermore Sonya (2006), also indicates that studies involving families in which more than one member is affected with ASD have provides information to conclude that: “the identical twin of an individual with ASD has better than 90% chance of being affected; a fraternal twin or siblings of an affected individual has 15% chance of having ASD; and ASD parent has a 10% chance that his or her offspring will also have ASD”.

Some studies describe the causes of autism in relation of environmental risk factors. The following sections discusses about the environmental risk factors in relation

of autism. Fombonee (2006) demonstrated the cause for autism to be considered is prenatal exposure to teratogens that an environmental agent that can cause abnormalities in developing fetus. Sonya (2006) showed that exposure to cytomegalic virus and rubella during early pregnancy is tough 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.

Studies reveal exposure to pharmacological agents specifically during pregnancy represents a highly related to environmental issue to the risk of autism as teratogen. Such as Dietert and Dewitt (2010), indicated the changes in availability and use of certain prescribed drugs and non-prescribed drugs such as thalidomide and VPA are among them.

Autism is becoming more prevalent these days .Study conducted in USA revealed that it has been found that children 18 years of age and under, the prevalence of autism range from five cases per 1000 to 60 cases per 10,000(Altieri& Kluge, 2009).According to Autism Developmental Disabilities Monitoring (ADDM) Network indicated an overall prevalence of ASD to be 9 in every 1,000 children (Rice&CDC, 2009).

Rice & CDC (2009) examined that the role of gender in prevalence of autism, with more boys being diagnosed than girls. It indicated the prevalence of ASD in males ranged from 7.3% in Florida to 19% in Missouri whereas the ASD prevalence among females ranged from 1.0% in Florida to 4.9% in Arizona. This brought the overall prevalence ratio across all sites 4.5:1 with males obtaining 4.5 and females obtaining.

Available literature analyzed that the prevalence of autism spectrum disorder among Africans living in Africa differs from that among living outside the continent and

will be reviewed separately in the following paragraphs. A literature review to date shows no school or community based epidemiological studies of autism spectrum disorders in Africa continent. The only available study that is closely related was focused on prevalence of ASD among children with developmental disorders in Arab countries (Seif Eldin *et al.*, 2008). This study however included two Northern African countries, namely Egypt and Tunisia, with predominantly Arabic populations. Prevalence of autism spectrum disorders among children with developmental disorders in Egypt and Tunisia were documented to be 33.6% and 11.5% respectively.

In Ethiopia there is no any statistical evidence to know the magnitude and prevalence of autism spectrum disorder. Though, Nia Foundation (2012) documented that autism is prevalent like other countries. As a result, if one in every 115 children is diagnosed with autism in USA, with the population 80 million in Ethiopia, it is estimated that there are around 530, 00 children with autism and related developmental disorders.

2.2 Reaction of Parents to Child's Diagnosis with Autism

The diagnostic examination is essential for parents to assure the fit between the observation of unusual child behavior and real entity. The reaction of families to the diagnosis varies from individual to individual. The families experience a range of reaction to the diagnosis of autism from extreme shock, grief or denial to relief and happiness in other extreme (Siegel, 1996). Similarly, Altieri (2006) studied many of American parents experienced despair, sadness, denial, confusion and anger when they revealed that their child had autism. Correspondingly in Scotland, phenomenological research by Kristen (2008), demonstrated that some parents found perceive the result of a diagnosis as significant and stressful life event. To the parent's diagnosis meant a sudden

loss of the potential for their child to achieve all things they take for granted, like living independently, getting married and having children.

Parents are relieved that they were given an answer in regards to their child's symptoms but this does not erase the stress that they endure while raising a child with autism. Parents often experience stressful situations upon the initial diagnosis that relate to their child's behavior, adapting to this new lifestyle and the complexity of finding access to the appropriate services useful to the family(Banach *et al.*,2010). In the same way, in a Zambian phenomenological study that investigated parents' lived experiences in 17 educated and urban parents of children with autism stated that the reaction of parents to the diagnosis ranged from relief to confusion and fear for the future of the child (Joachim and Robert, 2012). Hartmann (2012) also revealed that parents whose child is diagnosed with ASD experience difficulties and it changes the dynamics of the family. Everyday activities of the family need to be modified and the child with ASD will need extra attention from the parents. While parents recognize their child is autistic that can result in scattered emotions for parents. Moreover, a study by Angela (2013), conducted on 13 Jamaican mothers raising children with autism also validated a range of emotions immediately following the diagnosis including despair, sadness or being overwhelmed at the news.

To condense, the recent literature reviewed by the student researcher shows that families and individuals vary in how they react to autism spectrum diagnosis. Sometimes, it comes as a relief, with parents having an explanation for the difference that they see in their children. On the contrary, other reaction may include devastation, grief, disbelief,

anger and helplessness. While parents may come to terms with the diagnosis, other family members may find it very difficult.

2.3. Parenting Children with Autism Spectrum Disorder

Parenting starts while there is plan for it that changes how people define themselves and changes consequently appear in their priorities and principle of life. As result, before their baby is born, many parents prepare themselves psychologically, economically and socially for making lifelong commitment to their baby by preconditioning themselves by a lot pre expectation. They expect healthy and lovable baby. Becoming a parent can be seen as opportunity and challenge. It can be an opportunity by providing aims to pursuer that donates to parents' understanding of purpose in life, nourishing human needs, pervading positive emotion into a parent's life and heightening a parent's identity with multiply social roles and enhances life satisfaction. It can also be a challenge as result of tiredness and being fidgety because of many chores, frustration, financial strain, strained parental relationship and excessive worry about children's safety (Nelson, Kushlev and Lymbomirsky, 2013).

Most research has made known that parenting child with special needs is more challenging. Having a child with developmental disability challenges parents by blighting their expectation for their children that can lead to fear for the future of their children; and emotional distress in many domains of their lives (Gona, Mung'ala-Odera, Newtown and Hartley, 2011).Correspondingly, Aadil *et.al.* (2014) found that parents having children with ASD face many challenges such as the child's character cannot along with everyone in this way parent's obligated to teach their child to communicate, teaching basic life skills and preparing their child for adult life.

2.3.1 Parental Stress

Parenting Children with autism spectrum disorder (ASD) be more and challenging than parenting child with typical development. Parenting a child with a disability can produce greater stress and sense of imbalance in the family system. Even though they have the joy of being able to hold and love their baby, their life is suddenly and drastically changing (Hartmann, 2012). This in turn produces feeling of grief, stress and confusion. Instantaneously, with no precondition and preparation, the family has to adapt new life style. And also daily routines become much more complicated, at least the primary care giver to resign out from their work and families find them no longer able to do some of the things they were used to.

Autism Society (2012) reported that it is common that children with autism are nonverbal and unable to express their feelings and thoughts. This might bring frustration for both the parents and children since the parent experience difficulty in understanding the needs while children experience difficulty expressing their own need that often lead the child to aggressive behavior. In most cases parents have always experience extreme worry as the children unable to report any form of abuse.

Angold *et al.* (1998) stated that parents of children with special needs undergo through a lot of strains because of unusual demands that comes with the child with special needs, financial difficulties and guilt. In this way, Richmond, Brain and Pena (2009), showed that parents experienced numerous types of stress such as depression, anxiety, frustration, social isolation and spousal relationship problems.

Furthermore, mothers of children with autism make the most intense adjustment to a child's developmental disability and they are at a higher risk at long term stress than

fathers (Nisha and Susan, 2010). Mothers of children with autism 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 with their normal life(Hosseini, Ayyub,Jail and Nafiseh,2013).

2.3.2 Causes of Parenting Stress

One of the main causes of parenting stress is their child's inability to express their basic needs. This brings frustration for both the parents and the child. The parent's experience difficulty to elucidate the need of their child diagnosed with autism while the child will experience difficulty expressing their own needs. This might often result in aggressive behaviors for the child diagnosed with ASD as parents may be unaware if their child is hungry, sick, tired, hurt, sad or mad. This is especially stressful for the children who are non-verbal. Extreme worry may also present in parents as neglect in other settings. Parents experience worry and concern that their child may be potentially harmed because often, they cannot communicate verbally and are highly vulnerable (Autism Society, 2011).

Similarly, Devis and Carter (2003), the most consistent predictor of stress for mothers was a child behavior. Mothers of children with autism have reported that their children had low levels of social relatedness also presented higher levels of overall stress. In particular, mothers were stressed by the issues related to their children's regulatory problems (e.g., sleeping, eating and emotion regulation) as well as externalizing behaviors. As narrated by Weiss *et al.* (2014), parents of children with ASD experience high level of stress, depression and anxiety that could have significant influence on

parenting. The challenge faced by the parents is extreme if their child poses typical ASD symptoms such as emotional, behavior and communication problems that bring family crisis. Likewise, Family recreation is one area that can affect by the ASD because due to the unpredictable behavior of the child that some children with ASD often exhibit. Emotional and mental health of the parents is also an area affected by the child's ASD.

Second cause of parenting stress is taking their child diagnosed with autism out in the community. Because of the awareness autism is not well known that may results members of community may not understand or be sensitive to the behaviors that may occur. This also creates parents cautious to take their kids over to friends or relatives houses because they feel as though they cannot socialize or relate. These reasons sometimes leave parents experiencing a sense of isolation from their friends, family and the community as well (Autism Society, 2011). Equally, public attendance is an issue significantly influences social life of parents of autistic children. Because families develop the feeling of fear in which children behavior and action might negatively understand by other people, as result parents prefer to isolate themselves instead of facing the reality of taking their child in public. Moreover the low level of to acquire social recognition from the society which let parents to experience social stigma and embarrassment associated with the characteristic of the autistic children displayed (Altieri, 2006).

A third cause of parenting stress is the concern for their child's future welfare. Parents provide the best care and understand their children. They experience fear as they plan for their children's future and examine ways of proper care. Some children, depending on their developmental ability, may need toileting and bathing assistance.

Further care giving presents stress in parents because in certain circumstances, there are no other family members capable of taking over when the parents are no longer able to care for their child (Autism, 2011).

Fourth cause of stress for parents is the financial aspect. A child diagnosed with autism needs several services to assist in their care and often times are financially stressful for the parents. A child with autism may need follow up, home programs and various therapies which can be expensive. If one parent has to give up his/her to help with care giving, this can be financially stressful as it leaves one parent to support the entire family (Autism Society, 2011). Likewise, Sharpe and Baker (2007) indicates that many of intervention strategies require long hours one to one interaction with a trained therapist and use of expensive food and drug supplements. As autistic children need lifelong treatment that induces parents to spend their time and money for long period of time.

Finally, feelings of grief can be stressful on the parents. The 'typical' child parents were expecting is no longer reality. They are faced with the loss of lifestyle and drastic changes in their family dynamics. Parents grieve the loss of the child they expected for themselves and their family. These feelings of grief can occur throughout the parent's life as different events can trigger the grief. Some triggers include birthdays, holidays, continuous care giving, weddings and reproduction (Autism Society, 2011)

2.4 Parents' Experiences of Raising a Child with Autism

The grieving process associated with the birth of a child with disabilities is complicated by the parents' inconsolable the death of the "expected" baby while at the same time trying to accept the "imperfect" baby. Even though they have the joy of being

able to hold and love their baby, their life is suddenly and drastically changed (Hooyman & Kramer, 2006). This in turn produces feelings of grief, stress and confusion. Immediately, with no warning or preparation, the family has to transform and adapt to new life style. Daily routines become much more complicated and families find they no longer able to do some of the things they were once able to do (Meadan et.al. 2010).

According to Hartmann (2012), parents whose child is diagnosed with ASD experience difficulties and it changes the dynamics of the family. As result everyday activities need to be modified and the child with ASD will need extra attention from the parents. Learning that their child is autistic can result in scattered emotions for the parents.

Moreover most parents with autistic child have little awareness about autism (Paul, 2001) and this limited awareness of autism by parents led to initial reaction of denial, fear, and shock during and after diagnosis (Lindsey and Roberta, 2013). These parents are generally left in tremor and disbelief after diagnosis not knowing what course of action to take to help their autistic child and their families (Paul, 2001; Hossein, Ayyub, Jalil, Nafiseh, 2013). So, afterward getting the diagnosis process, many parents testified that they wished they had received more information surroundings resources, treatment and prognosis for their child B (Lindsey & Roberta, 2013).

Children diagnosed with autism often follow specific routines in their everyday life. One study indicated that parents have to rearrange their daily routines to accommodate to the child as the child is unpredictable and often unable to regulate their behavior. Parents reported that routines were much easier to follow in familiar space such as their own home, however more difficult in unfamiliar places such as another relatives'

home or out in the community (Schaaf *et al.*, 2011).As the result the parent often feared that if the child becomes deregulated, the child would damage anther's belongings. In unfamiliar places, parents often don't have the tools needs to prevent or cope with disturbances that could possibly set off the child. This resulted in parents talking less family vacations, attending limited community outing and isolating themselves from family and friends (Schaaf *et al.*, 2011).

Parents find morning routines as the most difficult as most meltdowns .During this time due to sensory causing the child to be late for school and parent to be late for work .Equally, mealtime was challenging as a child diagnosed with autism can be sensitive to textures of food ,often refusing to eat(Schaaf *et al.*,2011).

Compared to 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 educational services and limited access to the available resources that are concentrated in the urban areas makes it difficult for families of African children with ASD to get them necessary intervention and educational programs.(Mashudat *et. al.*2013).

Studies from Africa such as Lara(2007) and Anthony(2009) 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 studies reported that they had no awareness about ASD which led them to poor parenting, psychological distress, strain on the marital relationship and relationship within the family.

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

Mashudat et.al (2013), explained autism in Africa the child with neuro-developmental disorder seen as a mark of shame on the family due to misunderstanding of the etiology of various developmental disorders. Therefore, individuals with ASD and their families are faced with negative attitude, avoidance, denunciation as well as destructive and offensive comments which lead families to hide the child from the society. Similarly, several parents from Zambia also stated that the burden of responsibility for their ASD child was worsened by unsympathetic comments from the general public which shows that many not aware of the ASD condition and stigmatizing the child and the parents occur (Joachim and Robert, 2012).

Angela (2013) also demonstrated that many children diagnosed with ASDs living in Jamaica have very limited access to educational settings. Most mothers of children with autism reported that it became challenging to find respite care, appropriate educational settings for their child and that most educators and schools are extremely under prepared for supporting the needs of children with ASD and the relatively high costs of educating a child for families.

2.4.1 Ethiopian Parents' Experiences Raising Autistic Child

The history of people with special needs in Ethiopia is not different from other developing countries. Children with special needs are among the most disadvantaged

social groups in every dimension(Weldeab, 2006).This means to be special needs, usually denoted to be discriminated against as well as exposed to social isolation and physical restrictions (Letekidan, 2003).

People with special needs in developing countries have been encountered various challenges due to governments of those countries had limited space to the policy formulation and implementation for these large groups of citizens.

A child with autism has posed its own influence on the family. In country like Ethiopia where physical or mental impairments are viewed as things related with curse or some sort of bad omen .There are tiresome contribution to create opportunities to make life better or improve the situation of people with the problem though the challenges has been severe. The psychological and emotional stress by parents of children with the problem is immense (Letekidan, 2003).In the line of this, Nia Foundation (“n.d”, Autism in Ethiopia, Para 6) denotes in particular, mothers of autistic children who have lost their spouse due to diseases or who are victims of spousal abandonment due to their child’s disorder are left with few resources. With little explanation for their children’s behavior and few sources of assistance as result they obligated to carry incredible burden. They remain without any support and left alone in the dark. Parents are unable to work because their children are often not allowed to attend regular schools for children in their age. 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.

Likewise, the impact of autism on mothers is expressively visible on their daily routines and life experiences. And also, most mothers of autistic children experience a lot

of challenges which let them to do not at ease 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. Hence, thousands of children with autism are confined to their homes with no access to education or rehabilitation.

Handicap National (2012) reported that in one of the Woredas in Addis Ababa it was stated that some parents are not willing to send their children to school or to play for fear of being endangered, hurt and segregated. These parents face challenges in rearing children with developmental disability and they may not send the children to school because of number of reasons, such as, the education of the child with special needs may not be the priority for the parents whether their child can be schooled or not; the parents perceive the child may not receive the necessary support; fear of shame and guilt and etc.

Aynalem (2014) demonstrated that the family of autistic children facing a multifaceted challenge in and after the diagnosis process. The complication related to tiresome diagnosis process and lack of psychosocial support risked family to experiences stress, shock and anxiety. In public places also community has low awareness of autism that result most families are in fear or afraid to appear in public. The participation of families in social life is limited by caring a child diagnosed with autism.

Helen (2016) describes the experiences of mothers' in raising their autistic children which they have been facing a lot of challenges in relation with their personal and social life. The challenges manifested through in their relationships with spouse and affects siblings as the mothers of children with autism give more time, attention and commitment to their child with autism that can have high influence in their personal and social life.

As compared to previous days, today in developed countries, there is a growing awareness of the particular needs and challenges that a child with autism fronting with continuous research, skilled professionals and more effective techniques for treatment has been developing. Thus; the future of child with autism is far more promising. Unfortunately, children with autism in Ethiopia are still the most forgotten and vulnerable once. 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 the result, children with autism have been deprived of the opportunities to gain or improve their academic social and communication skills (Joy Center for Children with Autism and Related Developmental Disorders [J-CCARDD], 2005)

Some local researches illustrate that most serious and common challenges parents of the children with autism face in countries like Ethiopia relates to access to professional information and services. Most parents have no accurate and update information about their children's developmental disorder because the service system is usually limited and fragmented. (Amalkelew, Daniel and Fasikawit, 2000).

Equally, thousands of children with autism are confined to their homes with no access to education or rehabilitation (Tirrussew, 2005). Because of lack of awareness, families and children with autism are often blamed for their actions and disorder is sometimes seen as punishment for some spiritual wrong doing (Letekidan, 2003).

Parenting needs skill that learned through life experiences and education. Ethiopian young mothers often learn the parenting skills from their home environment especially from their parents, grandmothers, elder sisters and etc. Nonetheless, the

challenges of parenting children with developmental disabilities require an advanced skill which parents should receive from all sides to counter and cope with the negative community attitudes and traditional beliefs towards disability. Consequently, 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 advices can prepare parents with better skills to identify their psychological challenges (Amalkelew, Daniel and Fasikawit, 2006).

Charnet and Opdal (2007) smeared 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 different means. By working within the cultural traditional institutions of Ethiopia[e.g., "coffee mornings"] and utilizing traditional social institutions like " idir", "equab ," "senbet", "mahber" can change the perspective of parents as well as the larger society from the stigmatized negative stereotypes that seem to pervade the society's reference to and treatment of children with cognitive disabilities towards a more strength based perspective.

2.5 Coping Mechanism of Parents of children with Autism

In the light of the importance of the cause of stress, challenges and reaction of parents of children with ASD to theses stressors, a number of studies have focused on identifying coping strategies used by parents of children with ASD. Number of researches that the student researcher reviewed identified coping strategies parents employ to cope with the stressors of raising a child with ASD. There is no sole strategy

found to reducing or coping with parents' stress rather several coping mechanisms were found to be effective. Thus, some of the coping strategies across recent literatures are discussed in this section.

Coping involves psychological, social resources and strategies that help to eliminate, modify or manage a stressful event (Nabway and Ahmed, 2012). Hastings and his colleagues (2005) explore the structure of coping strategies used by parents of children with ASD. Carver, Scheier & Weintraub (1989) indicate the four coping dimensions pertinent to mothers of children with ASD could be identified: active avoidance, problem focused, positive reframing and religious coping. Hastings et al (2005) also looked at the effect of coping strategies on maternal stress. Only active avoidance coping was found to significant maternal stress.

Lyons *et al.* (2010) looked at coping styles as moderators of the impact of child symptom severity on stress in parents of children with ASD. The study comprises three scales: emotion-oriented (focusing on reducing the emotional tension caused by the stressor, e.g., crying, becoming upset), task-oriented (working at solving the problem), and avoidance (either via social diversion or via distraction).

Some studies have identified additional coping strategies and found these to be linked to parental stress. For example, Luther, Canharn and Cureton (2005) found positive reframing i.e., how one perceives stressful events and their situation) predicated lower levels of stress in parents of children with ASD.

To summarize, Literature in this area continues to show that, whether parents, clinicians or teachers rate them. More importantly, regardless of differences in the

measures used to assess the severity of a child's with ASD, symptom severity continues to be a significant cause for maternal stress, coping strategies employ by parents.

2.5.1 Social Support

The core deficits of autism have been found to be associated with increased feelings of parental distress they can also be the catalyst for families seeking out supportive networks. Colin and Kathleen (2008) indicate social support is the major coping mechanism in moderating parenting stress and daily negative mood. According to Fischer & Corcoran (2007) viewed social support has been found in several studies to be an important safeguard against family crisis and to be as a tool that promote family resilience and recovery in the family of children with autism.

Studies discusses on several types of social support, both formal and informal. Schopler & Mesibov (1984) define formal social support as an assistance which is social, psychological, physical or financial support that is provided for free or in exchange of fee through an organized group or agency, while informal social support as relationship which may include immediate and extended family, friends and neighbors.

Myers *et al.* (2007) stated that parents of children with autism get primary support from their immediate and extended family and friends who provided emotional and psychological informal support while parents may get support from local organization that give to them formal social support such as training, interval care and arranging social events.

Researchers have been highlighting the use of social support by families of children, specifically the impact of social support on mothers of children with autism. This choice may reflect the mother's traditional role as primary caregivers, particularly

when the child has disability or it may suggest that social support impacts on mothers and fathers differently; however, the importance of social support in the overall wellbeing of the mothers of children with ASD is clear (Boyd,2002).

According to Gray and Holden (1992) mothers who get higher level of informal and formal social support reported lower levels of depression, anxiety and anger. The study also found out that social support served as the most powerful predictor of depression and anxiety in parents of children with autism. Furthermore, the inability to locate or access social support can affect a mother's overall wellbeing. Informal maternal support comes from the spouse or significant other provides some of the most beneficial support to mothers (Herman &Thompson, 1995).

Heather et al (2010) showed that mothers who get support from their spouses get high sense of relief that can be viewed as significant emotional support. Altieri (2009) also found that mothers who more likely get social support from their spouses during the times of crisis gain more confidence and have low stressed life style.

Equally, according Durban *et al.* (2012) mothers tend to get closer to the family for support while fathers tend to run away or created space between them and their family because they do not realize how to cope up with the situation and sometimes they would have the feeling of blaming their wife for disability of their child. Furthermore, Angela's (2013) indicated that mothers who have access of information and social support from professionals and families have low level of stresses.

2.5.2 Religious Coping

Religious coping employs religious beliefs and practices to cope with stressful and devastating life situations that help people to come up with their difficulty. Pargment

(1997) defines religion as “a search for significance in ways related to the sacred”. Religious coping strategies play a vital role and serve as an important resource in parents who are raising autistic children. Religious support can be delineated by perceived support from God, church and support from one’s congregation.

Durbanet.al. (2012) indicated that most parents use religion as coping mechanism which can provide them strength while they encounter various challenges of taking care of their autistic children. Similarly, Gona *et al.* (2016) also found out religious coping strategies serve to the parents as emotional aspects that concern the appeal to God, with the faith in supernatural powers, prayers and request for spiritual healing. Most parents believe that autism is come due to predetermined God’s plan; hence, they cultivate expectations also for his intervention in resolving the problem. That is to say, the confrontation strategies aim at the child’s physical health and parent’s psychological wellbeing through faith and praying.

At this glance, Bashir ,Khursid and Qardi (2014) explores that religious faith as parameter for enhancing parents’ resilience and belief that there is relation between the divine will and the origin of autism. According to Tiffany (2010) bible study and attending in any kind of fellowship in church that make parents to restore their patience, stress management and change their view about their life. Latafa’s (2014) also indicated that positive reappraisal and spirituality was the most commonly used coping strategies in parents of children with autism.

2.5.3. Family Resilience and Positive Appraisal

Several studies suggested that families with a child with ASD become more resilient as a result of their coping with the illness. According to Wickham-Searl (1992)

the uniqueness of parenting children with disabilities allowed women to transfer their knowledge, information and skills from their own homes to other families with similar kinds of problem. Likewise, Bayat (2007) presented that many families of children with autism display characteristics of resilience and gaining strength as result of the child's disability. Nisha and Susan (2010) indicated that mothers of children with autism use positive appraisal (constructing positive outlook to the context) as a coping mechanism to their stressful condition while raising autistic children.

Parents of children with autism use various numbers of positive changes emerge in their lives which come due to reassess and revaluation of their life and become more resilient and develop positive outlook for their situations. Moreover, Sivberg (2002) demonstrated that parents of autistic children who developed flexibility, patience, problem solving and understanding the unique qualities of their autistic children that open a new path to develop their parenting style with dignity and resilience.

2.6 Theoretical Framework

2.6.1 Ecological System Theory

The ecological perspective was developed by the renowned developmental psychologist, Urie Bronfenbrenner in the 1970's to help understand human development across the life span. According to Bronfenbrenner (1994), human development can be better understood when the whole ecological system that support growth is put into consideration. Thus, growth occurs in humans when there is an active and reciprocal interaction between individual and other persons or other entities within immediate environment. The system is made up of five (5) subsystems that are socially constructed development; micro system, mesosystem, exosystem, macrosystem

and chronosystem. For the purpose of this study, only the first four systems would be considered.

Microsystem

The microsystem consists of interactions that are face –to –face as, those that exist between family, friends and workplace. This is the immediate environment of an individual where events relating to the child have a more direct effect and vice versa. This explains why mothers, spouses and other members of the family are affected by the presences of a child with autism. Moreover, how spouses and other member of the family support mothers in their adversity of raising autistic children. For example, mothers might experience stress, change routines or adjust their work time to accommodate the needs of the child with autism. Based on the responses from the microsystem, the development of the child with autism and their mothers can equally be stimulated or restricted. The microsystem in the ecological model is particularly helpful in understanding the impact of child with autism on mothers. This system also enables to view how mothers and their families mobilize resources to ensure equilibrium.

Mesosystem

The mesosystem reflects interaction between microsystems. Bronfenbrenner (1994) explained this system comprises the linkage and processes taking place between two or more settings containing the developing person. The relationship between mothers and various system like work, religion, school and hospital. The quality of the relationship within this system is critical for the resilience process of mothers. Although, it is common for every mother to have interaction with other microsystem, Mothers of children with autism experience increasing pressure from these relations which can either

improve or hinder mothers' strengths. For example, due to the difficulties in mental process of children with autism, a school or autism center which is more accommodating can help mothers know that their child is safe and developing in the right direction. However, stress can increase if the school or autism center becomes less accommodating a situation that can hinder the process of resilience. Considering the mesosystem in relation to mothers and their child with autism, it is critical in understanding how interactions among microsystems have impact on a mother's ability to remain strong and functional.

Exosystem

In the exosystem, there are linkages and processes existing between systems of which at least one does involve the child with autism (Bronfenbrenner, 1994). Nonetheless, any transaction that takes place has an indirect impact on the autistic children or their mothers. This system includes social services, schools and extended family among others. Social services might work with autism centers to provide the needed support to facilitate learning of the child with autism in center or school. This might not directly involve the mothers but the outcome of this result could affect them positively or negatively.

Macrosystem

The macrosystem represents the larger context within which micro, meso and exosystem operate. According to Bronfenbrenner (1994), it encompasses cultural beliefs, social policies, customs and norms that define a particular society. Amankwa (2015) added that, identifying a unique feature of macrosystem affects processes within the microsystem. In the context of Ethiopia, there are policies provided by the government to

support persons with disability. Besides, macrosystem includes the cultural belief society has significant impact on the experiences of mothers raising children with autism. The macrosystem is therefore, useful in understanding how structures within the larger society operate directly or indirectly to promote or hinder resilience in mothers of children with autism.

In general, the ecological theory is useful tool for understanding how different systems within society or person's environment operate to help mothers to develop through h life and manage daily struggles. As the theory explained the systems are interrelated and interdependent within the society, which suggests that changes at one level affects the other directly or indirectly.

2.6.2 Strength Perspective

The strength perspective began to recognize and value the resilience's and resourcefulness possessed by many people living in adversity. Resilience is concept that used to describe people's ability to deal competently with risk, to overcome hazards that help them to continue functioning under pressure (Saleeby, 2002). Thus, strength perspective is about discerning resources and potential they have reversing stressful situations. Though the perspective focus on strengths and capacity, it does not however overlook traumatic events and its effects on individuals .It just call attention to balance where professional and researchers do not only preoccupied with the challenges of individuals, but also make conscious effort to identify strengths and build on them to cope up with adversity.

A strength –based approach is therefore essential in the study of resilience as it tunes researcher's attention to the ways that mothers of children with autism that enable

to assess the ways of coping and resilience in their long-life journey. As strength thinker, this approach served as a guide in recruiting mothers bearing in mind that no matter their struggle, mothers still process strength which help them to manage the daily struggles of raising a child with autism.

2.7 Summary and Implication

To summarize, the recent literatures reviewed by the student researcher demonstrates that over the last decade the number of families influenced with ASD has risen. To this end, families who raising children with autism have been experiencing various challenge. In addition, reviewed literatures provided more evidence for the significant stress families, mothers in particular has been experiencing. Most studies reviewed revealed that parents of children with autism developed various coping strategies for their stressors. Moreover; these studies showed that there is positive relationship between coping strategies and parental stress. Some studies suggested that coping strategies are complex phenomena and may have different capacities on the parental stress.

The implication of the reviewed literatures indicated that social workers play a key role in assessing parental distress, as well as restoring families functioning. Finally, the Ecological system theory and Strength perspective promotes resilience among mothers who raising children with autism. These theories strengthen the mothers raising autistic children by allowing them to live a more fulfilling life. Moreover, these theories give an implication on the role of social work profession play a vital role in developing intervention that target healthy family functioning. Interventions that are aimed at

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increasing family resilience as a means to decreasing parental stress need to focus on providing parents with coping skills need to directly impact their own wellbeing.

3. CHAPTER THREE: METHODOLOGY

3.1 Study Design

Study designs are plans and procedure that involve decisions of basic assumptions to detail method of data collection and analysis (Creswell, 2009, p.3). In choices of research design philosophical world views are basis for selecting research design to a study a topic. Philosophical world views are postpositivism, constructivism, advocacy and pragmatism. In conducting this study social constructivist philosophical world view used as road map.

According to Creswell (2014), social constructivism is world view that individuals seek understanding of the world in which they live and work. They develop subjective meaning of their experiences that directed toward certain objects which are varied and multiple, leading the researcher to look for the complexity views rather than narrow the meanings into few categories or ideas. By using the social constructivist philosophical world view the research seek to understand the meaning of various dimension that mothers of children with autism are facing.

The purpose of this study was to examine stress and resilience of mothers who raising children with autism spectrum disorder. Therefore, qualitative research was the most suitable method to achieve the study goal. Qualitative research is used to get detailed understanding of the issues and it provide a means for exploring and understanding the meaning individuals or groups ascribe to social or human problem (Creswell, 2009).

Similarly, qualitative research enhance knowledge through a continuous and extensive exploration which allow how people construct meaning to a shared

understanding feeling or perception of a situation (Johanna and Alison, 2006).Hence, a qualitative design is identified as the most suitable to meet the research aim of exploring the meaning challenges, stress, coping mechanism and resilience inherent in the experiences of mothers raising child with autism deeply with small participants.

A qualitative research bases on the five inquiry approaches namely narrative, phenomenology, grounded theory, ethnography and case study. Specifically, the student researcher employed phenomenological research design to guide this study based on the research questions because, it is particularly effective at describing how things experienced by mothers of autistic children. Phenomenological research is an in-depth examination of an experience, directed towards obtaining meaning from the everyday lives of participants, especially those aspects relating to people's feelings about an issue, event or experience.

According to Deborah (2012) intended in her study 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.

3.2 Study Area

The study was conducted at Bright and Joy Autism centers .Bright autism center is established in 2016.Bright autism center is found in Hawassa, Ethiopia. The name of “Bright” means “free from darkness of the surrounding”. It is a native, non-political, non-religious and non-profit making organization. It acquired legal recognition by the ministry of justice as local humanitarian NGO in March; 2018.Nia foundation Joy

Autism Center is established in 2002. The name of “Joy” is derived from the name of “Jojo, joyful place” .It is a native, non-political, on-religious and non –profit making organization. It acquired legal recognition by the ministry of justice as a local humanitarian NGO in January, 2006.Thus, these study area selected to this study which provide support for autistic children and their parents.

3.3 Eligibility Criteria

The study examined the stress and resilience of mothers who are raising children with autism. The researcher has set inclusion criteria as the following way.

1. Mother who have autistic child.
2. Mother who is willing to be part of the study to share her experience.
3. Mother who provided care for two or more than years after the child's medical diagnosis.
4. Mothers who are getting service provision from Bright Autism center and Nia foundation Joy Autism center.

3.4 Participants

The main objective of this study was to examine stress as well as coping mechanisms that help them to strengthen their resilience that are employed by mothers of children with autism spectrum disorder to deal with their stressors. As result the target populations were mothers of autistic children who get services in Bright and Nia Foundation Joy autism centers.

All kinds of sampling in qualitative research focus on nominating relatively small samples even single cases, selected purposefully with a board general knowledge of the topic and who have share same experience (Patton, 1990). Specially, phenomenological

study recommends that sampling to be purposive that provide a way for homogenous as a small sample size that give a sufficient data on the given phenomenon (Joanna and Alison, 2006).

Likewise, Creswell (2007) showed that in the phenomenological study participants need to be best suited for the research topic that includes individuals who have common or shared experiences of a phenomenon. Sampling strategies used in selecting sample from the general population. As result the student researcher used purposive sampling as sampling strategies in this study. The concept of purposive sampling is meaning the researcher selects individuals and areas for the study because it can purposefully inform an understanding of the research and central phenomenon in the study (Creswell, 2007). This sampling strategy served to reach more potential participants. The student researcher used purposive non probability sampling technique to serve the intended purpose of this study from Bright and Nia foundation Joy autism centers. Moreover, purposive sampling strategies served to identify more participants that could also provide more information which possessing same experiences.

Phenomenological studies are not emphasized in numbers of participants who have had experiences but, it gives more focus on how many times the phenomenon makes it presence in description. Thus, based on the depth of the study one could use five to twenty participants, however using more sample size provide a way for the researcher to acknowledge the variation of the phenomenon, rather than better generalizability of the results (Giorgi, 2009). Due to phenomenological study design need detailed analysis of individuals transcripts that take a long time .The student researcher used ten mothers of children with autism as participants of the study to meet the objective of the study .As

many researchers recognized that this can be realistically be done on this amount of sample size. Besides, sample sizes in qualitative studies are often determined on the basis of theoretical saturation. This point out data collection process while, no new data longer bring additional information to research question (Englander, 2012). Small sample sizes are the norm in phenomenological research design as the analysis of large data sets may results in the loss of the potential sounds of the meaning of the study (Collins & Nicolson, 2007). Therefore, the student researcher identified ten mothers of children with autism that diagnosed their children on the spectrum who are aged from 4 to 17 at Bright and Nia Foundation Joy autism centers.

3.5 Data Collection Procedure

Few months before data collection, I meet mother who has autistic child. She was close to my family. I told her about my research proposal .She gave me contact information of a founder of Bright Autism Center. I called the founder and took appointment to meet up with her and discuss about my research. She promised me to facilitate the overall process in the center .She was very cooperative .After the approval of my research proposal I took support letter from Addis Ababa University School of Social Work and I went to Hawassa. I schedule with the founder time to gather data. I was able to interview five mothers of children with autism.

I went to Joy Autism Centers before data collection. I was able to get the coordinator of the center. I provided the cooperation letter from Addis Ababa University, School of Social Work. She faltered to accept my request as she heard about it. She had fear that mothers of children with autism are get tiered of repeated interviews from researchers that do not have any contribution to them. She needed two weeks to a

decision. Finally she arranged time to interview mothers of children with autism who receiving services from the center .I interviewed five mothers of children with autism.

Moreover, I visited the centers that provide an opportunity to engage with participants' .It also paved a way to build strong relationships with them before the interviewing. I believed that rapport building before the interview led to enhance openness and willingness to engage with the researcher during the interview process. These exposures also provided me a way to the opportunity to engage with mothers of children with autism and to observe their interaction with their autistic children.

3.6. Data Collection Instruments

Qualitative research depends on multiple sources of data to obtain comprehensive understanding of the research issue. The data collection tools in phenomenological studies consist of in-depth interviews and multiple interviews with participants (Creswell, 2007).In this reason; the researcher used in-depth interview as primary strategy of data collection. The phenomenological researches tend to choose the interview due to their interest to get the depth meaning of phenomenon that experienced by the particular groups.

A semi-structured interview guide with open ended questions was used to conduct the interviews. This approach provided flexibility and allowed open conversations. It also allowed the student researcher and participants to build engagement. Prompts were used to invite the participants to talk about their experiences. This allowed the researcher to gather information with enough depth and quality to provide a detailed picture of the lived experiences of mothers who raising autistic children .Similarly, Smith and Osborn (2007) demonstrated that such kind of interview

allows the investigator capable to select interesting and essential area which promotes rapport. It also paves a way for greater flexibility of coverage and allows the interview to go into novel areas and tends to produce richer data.

Moreover, open ended question gave the participants the opportunity to respond in their own words rather than forcing them to choose from fixed responses and to make the interview information more exploratory in nature. The interview questions 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, the main causes of mother's stresses in raising autistic children in their lives and major coping strategies that help them to strengthen their resilience against their stresses.

Correspondingly, all interviews recorded to present more reliable evidence and avoid any bias which might happen if the researcher attempted to remember the conversation as Gray (2004) showed that taped conversations tend to present more reliable evidence than hastily written field notes. Besides, Field notes were taken immediately after the interviews to ensure all important observation. Furthermore, the student researcher used document review as supplementary data tools that enable the researcher to spent time to explore the available literatures published recently.

3.7 Methods of Data Analysis

In qualitative research, the process of data collection and data analysis are interrelated and often go on concurrently in research projects (Creswell, 2014). Thus, to analyze the data that collected from an in-depth interview went simultaneously with the

data analysis of the study. The researcher deployed interpretative phenomenological analysis to discover the fundamental themes. I ruminated that this technique was suitable due to its ability to give deep understanding of the participants' experiences about the phenomenon. The analysis process began by organizing transcription of audio records that was collected from in-depth interview by Amharic language. The transcribe tape record data translated to English by precise statement, leaving nonverbal and paralinguistic communication. Each transcript, then carefully be checked by assessing recording quality and the content of interview. At this glance, all interviews and field notes were transcribed using the Microsoft Word processing program. The transcripts were reviewed repeatedly for significant statements in attempt to find meaning and understanding through themes. Thematic statements were identified using selective highlighting approach .In this way, the search for themes of the experience involved in selecting sentences that stood out as thematic of the experience. Then each phrases and sentences that directed in viewing at the experiences of mothers of autistic children stressors, coping mechanism and the magnitude of resilience under study constructed.

According Creswell (2007) showed that the researcher needs to find all possible meanings, commonalities and different perspectives from these units of meanings. At that point, the researcher needs to take the context and process the participants in the study experienced with the phenomenon. This process provide away to get the essence of the meaning expressed in word, phrase, sentences, paragraph or significant nonverbal communication in which compression of what the participants by using the literal words of the participants. The participants' own words used to illustrate themes, able the reader

to assess the exact interpretations and provide an opportunity to rehearse the voice of the participants' personal experiences.

3.8 Ethical Considerations

Research process built a way by considering ethical issue. Ethical issues indicated by Lipson (1994) are informed consent procedures, confidentiality towards participants, trustworthiness, benefits of the study to the participants(as cited in Creswell,2007).Thus, ethical standards were maintained throughout the course of the project by considering the issue of written consent, confidentiality, anonymity, potential vulnerability ,and sensitivity. To ensure their consent, in addition to the oral consent, I read the written consent prior to conducting the interview. This offered me another opportunity to explain the all over purpose of the study. Besides, to ensure anonymity; pseudonyms were substituted for the participants and their children's names.

5. CHAPTER FOUR: Findings

Introduction

As stated in chapter one the major objective of the study was to find out the stresses faced by the mothers who are raising children with autism and explore coping mechanism that strengthen mothers' resilience against stress. Accordingly, this chapter presents the main research findings generated from the in-depth interview of mothers and analysis of their lived experiences. The first section is about the socio-demographic characteristics of the mothers having autistic children. Demographic characteristics included are: sex, age, educational status, occupation, the child's age and sex, as well as the accurate diagnosis. The next section looks at mothers experience during the pre-diagnostic phase.

Table one

Demographic Characteristics of Participants

Mothers'	Age	Mothers' Educational level	Mothers' Occupation	Current Age of the Child	Age of Child When Diagnosed	Gender of Child
Mother one (Birtukan)	40	grade 10	Cleaner	12	4	M
Mother two (Helen)	37	BA Degree	Nurse	11	3	M
Mother three (Meskerem)	38	12 Complete	housewife	12	3	M
Mother four (samerawit)	38	12 complete	housewife	12	4	M
Mother five (Seble)	31	Grade 4	housewife	17	2	F
Mother six (Betlehem)	38	BA Degree	Accountant	9	4	M
Mother seven (Abeba)	45	Grade 8	housewife	14	6	M
Mother eight (Gelila)	38	MA Degree	program officer	12	4	M
Mother nine (Martha)	35	PhD	Teacher	4	1.8	M
Mother ten (Meron)	34	Grade 10	Cook	10	7	M

*A pseudonym is used for each participant to keep their identity.

As can be seen in the table, the study involved ten mothers who are raising autistic children. The age of participants ranged from 32 to 45. All the participants were primary caregiver for their autistic children. Five participants lived in Addis Ababa and the other five in Hawassa. Almost all (9 out of 10) autistic children's gender was male; and their age ranged from 4 to 17 years.

Mother One (Birtukan):

Samson is my first and only child. I and my husband did not know about his situation. He showed some unusual behaviors, but we thought that he might not know the right and the wrong behaviors. I observed such kind of behavior since he was four. He was different and his development was behind the rest of his peers. He could not speak and communicate with us; he was very restless and became more aggressive, but unable to tell us why. His aggressive behaviors stood out most like: he scratched me and others, pushed me and throw things on me. We thought that maybe he is misbehaved because he is our only child. I tried to change my parenting style by showing him red flag. Though, his behavior could not change. When he wanted something, he never takes it himself; he always wants from me. In general, he tells what he wants by sign language. If he got mad, he hits me and he throws the thing he has in his hand. I get overwhelmed. I could not sleep at night because he had difficulty to sleep, he cries and screams extremely. I and my husband carried him on our back turn by turn till the night is over. When he was near four, he joined kindergarten schools. But he could not sit in class and he was just round the compound. His teachers complained about his behavior. One day his teacher told me that " Birtukan, you need to take your child to special need school around Mekanisa". After that I took him to Yikatit 12 hospital at the age of four. The doctor told

me that Samson got diagnosed. He prescribed for my child a drug that will make him to sleep and less aggressive.

Mother Two (Helen):

Elroi is my first child. I was concerned, that my son at the age of three and half, he was unable to communicate and restless. I suspected that there is something wrong with my boy. I always followed his routine; he loved to do repetitive activities and he cried without any reason. I decided to see a pediatrician. I expected something about his diagnosis. The doctor explained the problem as autism.

Mother Three (Meskerem):

Amen is the first child for us out of two children. My child was very active and playful. He was very normal till age three. I went to abroad when he turned to three; his father was in prison. The situation was very challenging in our family. My mother let him to join the school. Though, the teachers told her he began isolating himself, sitting down in corner, flapping his hand, he didn't want to play with his classmate and he was unable to sit. He rounded the school compound every day. He repeated words that he heard. He liked to play repetitive games. Even when I tried to talk to Amen via phone, he could not talk to me. I got frustrated and came back to my country. When he got me after 5 years, he did not get surprised; he did not even say anything about it. I suspected something is going on with my child. I took him to Yikatit 12 hospital and the doctor told me he diagnosed with autism.

Mother Four (Samerawit):

Abel is my first son. He is a very adorable boy. We had no idea that my first child is an autistic; because he started to walk at 11 months, he can able to talk until he turned to

two. The first suspicion was that his behavior is totally different from other children that I knew. He did not look or respond when I called his name. When he did talk, his words were hard to understand. Any kind of changes made him upset. Without any reason he started to cry and hurt himself. Then I decided to take him to hospital when he was four. The doctor told me my child was diagnosed with an incurable developmental disorder for a life time.

Mother Five (Seble):

Selam is my first child. When she was two years old, I observed some different behaviors like she did not want to play with other children; she could not able to sit on one place. She cried a lot. When she was two years and half; I took her to Tikuir Anebsa Hospital. I had already expected something was wrong with her. But I never expected autism. The pediatrician explained the problem as impaired brain development and autism is life time problem. He told me that the surgical procedure was appropriate treatment if it was before 2 years, since it is too late to carry out surgical procedure at her age.

Mother Six (Bethlehem):

Henok is my second child, from three children. He was born premature, during the eighth month of my pregnancy. By the time he was two, he was then at that point totally silent. He cried a lot. He was cranky and pretty obsessive with certain things. Then I decide to take him to hospital. The doctor told me that he might have slow development than other children. I was waiting him till he was three. Though, there was no any change .I went to the doctor who used to follow up since my child was born for medical examination of my son. The doctor did not respond to my early concerns, He

assigned prematurity of my child's development as reason. The doctor did not explain about autism. I did not know what to do because nobody could tell me: This is the next step. Nobody could really guide me to what to do. That was frustrating!

Mother Seven (Abeba):

My child was not able to walk and sit on floor till he got 4. I used to carry him on my back where ever I went. I went to different hospitals to find solution. Through therapy and sport, he was able to walk. Though he was able to walk, he was not able to talk. I knew that my child had something wrong. I was not able to figure out what the problem was. His behavior after he started to walk became very challenging and unpredictable. He did not want to sit and play in one place. He constantly did strange things like if he gets mad, he likes to scream, disturbing and hurting himself, and smashed himself to the wall. I thought it might be he was discovering new things in his surroundings. Then I went to different hospitals. Finally; one pediatrician explained the problem as impaired brain development and confirmed the cases of autism and epilepsy.

Mother eight (Gelila):

Eyoab is my second child. I did notice that he was different from other kids. I realized the difference that stood out the most is that he was not making eye contact; he was not talking. He was not meeting the milestone at the age four. Since from his birth, he has medical follow-up in hospital because he has problem of spinal cord. I took him to Yikatit 12 hospital for his backbone. But the medical board told me that there is nervous system problem; thus, they could not conduct the surgical procedure in Ethiopia. They told me to wait foreign doctor to conduct the surgical procedure but it could not happen. I decide to see a pediatrician. He explained for me Eyoab had problem in communication

skill. He advised me to teach him some words per a day. He did not tell me anything about autism. I took him to other pediatrician and he generally told me that my child has impaired brain development. He did not say anything about autism.

Mother Nine (Martha):

Hannel is my second son. He is now four years old. We started to notice that his behavior was different from my first son and other kids; when he was one year and eight months. But I did not give much attention because he still was one year and half. However, my husband was very concerned about his behavior; so, he continued his follow-up. He did not have eye contact. He was not able to take part while we tried to play with him. My husband started to read more about his behavior. My family would always say, "Do not worry, boys take longer to speak, you are putting too much pressure". They pulled me to their thoughts. I worried that much like my husband. Finally, Hannel became two years and half; but there was no any change at all. We had always some suspicion that Hannel had autism but we were not quite sure. When he flapped his hands and when he made tip-top walk, we thought he played. But the intensity increases through time. His father started to read more on our son's behavior and action. To confirm the case, we started to search best pediatrician in Hawassa as well as Addis Ababa. Finally, the pediatrician confirmed the case was autism.

Mother Ten (Meron):

Binyam is my first child. I started to suspect when he was three. I tried to take him to hospital. But my husband refused because one prophet told us my child has a big promise that is given from God. He would always say "Satan will testify us". He did not want to accept our child is autistic. I tried to consult people but no one said something.

One woman who is raising a child with mental problem told me that “I took my child to hospital but there is no any change, do not take Binyam to hospital. Just pray for him!!” But things became worst; his behavior became more destructive and I could not control him. When he got angry, he bit me and bangs his head with wall. He is very sleepless. I have been with him day and night for the last seven years. Before he joined the autism center, the founder of the center took him to a hospital and the doctor confirmed that the case is autism. He joined the center when he was 7.

Themes Identified

The study examined the lived experience of mothers raising a child with autism. I also explored the mothers' stress and resilience in their personal journey in raising a child with autism. I identified three major themes and their subthemes. The following table illustrated these themes.

Table two

Major Themes	Sub themes
1. The Major Experiences of Mothers during and after the Time of Their Children's Diagnosis	Sadness, Despair and overwhelming feelings as Reaction by Mothers
	Lack of Information and Support during the Diagnosis
	Mothers' Suspicion Regarding the Cause of Their Children's Developmental Problem
	The “Lense of Autism in the Mother Eye”: Mothers perspective and Definition of Autism
	“New Motherhood”
	Positive Learning Experiences in Their Motherhood Journey
2. Causes of Stress in Mothers of Children with Autism	The Severity of Children's Behaviours
	Uncertainty about the Future Concern of Their Child
	Children's Inability to express their Feelings and Needs
	Inadequate Services

	Financial Difficulty
	Lack of Mother's Self Care
	Social Stigma and discrimination
3. Major Coping Strategies and Support Used by the Mothers' to Strengthen Their Resilience against Stress	Religion
	Social Support
	"Learning All you can"
	Acceptance and Cherishing little progress
	Focusing on Positives

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

The first research question intended to explore the long journey of the mother during and after the diagnosis of their children for Autism spectrum disorder. The purpose of this research question was to get a great insight what their experiences and the diagnosis process was like for mothers.

4.1.1 Sadness, Despair and Overwhelming Feelings as Reaction by Mothers

It was not easy for mothers to receive a diagnosis of autism for their child. As they realized that their motherhood journey would be different from what they had hoped for. Participants indicated they moved through a grief like process to the loss of a child they have expected to have. Participants reported they have experienced myriad of responses including hopelessness, shock and confusion to the question of "why me?" This led to the emergence of the first theme sadness, despair and feeling of overwhelmed as reaction by mothers.

For instance, Gelila said,

I have visited different medical centers and pediatrician; none of them came up with the diagnosis of autism. I did not get response from medical experts. I decided to read more. One day I watched Mrs. Zeni Yenus who is the founder Joy Autism Center in television show. She explained about autism and the characteristics of autistic children. I started to compare Eyoab's behavior based on her explanation. I called to Mrs. Rahel who is the founder of Nehemiah Autism center. She gave me detail information and explanation about autism. Then I confirmed that my child is with autism. I started to read more about autism on internet. My educational background helped me a lot. I was able to notice the clinical signs; Eyoab laughed, cried and screamed without any reason. I knew that these actions were related with the nervous system. There was no way out! I was so distressed, depressed and felt despair. I asked God " why me?"

Seble also said,

I felt devastated and helpless because I thought I could not bear the burden. I was 16 years old, young and could not articulate things very well. I gave birth without marriage and my families were not happy on that condition, and this issue added unto me. I got overwhelmed.

Birtukan said,

I actually broke down into tears. I became so emotional about it because I come to the truth. I lost my only son. There is a possibility that my child is not going to be normal. There was no way where to go?

Meron also reported,

I was very shocked. I believed that my son has God's promise unto him. I did not even, know about what autism was.

However, Bethlehem and Martha differed from the other mothers: they were not in emotional crisis. They moved forward to face the long journey from professional saying,

Bethlehem said that,

The doctor did not say anything about the case of autism. I get confused since I was not able to find any solution to my son's problem. I really was not aware of what autism was. One day I saw while a woman was being interviewed on television, she talked about autism. After that I started to follow up my child based on her explanation. I realized that my child showed the characteristic of autistic children. Then I decided to educate myself about autism. I read a lot of researches and watched a lot of videos to inform myself. I called to Nehemiah center and the owner of the center told me to bring my child to Addis Ababa. The psychologist diagnosed my son. He confirmed that my child is an autistic. The psychologist advised me that you need to train him very well. Then I just moved forward to train my boy and to let him be best person in the world.

Martha talks about “redefining the life”. She had for her son after receiving his diagnosis saying;

I came from a strong academic background. I already update and educate myself before the diagnosis. The diagnosis was taken when he was two years and eight months. After that I read the American Autism screening manual. I started to change my mindset and; home setting. I accepted it! I decided to change our lifestyle. I shifted everything based

on what Hannel need to acquire. I have to learn to let that go, I learn to appreciate what he is doing. What actually getting done!! It took for me long period of time to relate my life style and what Hannel needed to meet on his age.

In summary, mothers at the time of their children diagnosis, had a range of reactions including hopelessness, worry, guilt; but, they have been engaging in the process of redefining their vision for their children's future. It was found the above feelings the mothers faced after the diagnosis were difficult. Due to the fact that having received a diagnosis of autism mothers, generally do not know what to do next in order to help their child. They got overwhelmed by the prospect of diagnosis with no support, referrals or recommendation. This brought the second theme lack of information and support during the diagnosis.

4.1.2 Lack of Information and Support during the Diagnosis

Most participants reported that they were not getting enough information from professionals in the hospitals and clinics. This made the situation more challenging and exposed them to various psychological impacts. First as noted, Ambiguity was commonly mentioned with regard to determining the direction in which one should proceed in seeking treatment, information and related services. Second, all participants experienced a significant lack of professional counseling and advice. Especially getting trained professionals (like pediatricians and experts who specialize in the area of autism) was not easily available. Third, all mothers spoke of various treatment and service seeking. The barriers most commonly included waiting list and medical cost. Most interviewees in that each barrier in treatment and services seeking journey made their life more challenging.

Meskerem explained;

The doctor told me my child has been diagnosed with an incurable developmental disorder for a life time. I have no awareness about autism. I never heard the word before that time. I did not get any information and psychological support during the diagnosis. He just prescribed some medicine to let him sleep. I really did not know what to do and where to go!!

Helen recollected:

So the whole diagnosis process was very traumatic for me. May be autism is not prevalent or if that is the culture of the hospital, the doctor just told me my boy's diagnosis was autism. He gave me the report to read. That was how I found out! As a mother, it was very strange for me. Even though, I had medical background. I was not able to understand the situation. I never and ever expected. Start to think about it and you are like "what am I going to do?", "what is he going to do?", "what is he going to become?" That was my process. I just put down in island. No one lifted me up! It was also very difficult to get autism center in our country.

Gelila stated:

I have visited different medical centers and a lot of pediatricians, none of them came up with the diagnosis of autism. I did not get any advice from medical side. Then one doctor recommended some medicine supplement to address my son challenging behaviors.

The discussion about the experiences and reactions of mothers at the time of diagnosis led to question of what they did next to support their autistic child. This question found out mothers proceeded to next measures to help their children. Birtukan explained her next step in the following way. She said:

I was trying to find remedies for my child. I took him to various protestant churches for prayer and healings, monasteries, churches continuously. I thought he might get cure by the spiritual but, there is no any change. I gave up on God!! Then I started to search autism centers. I got the Joy Autism Center. But he was in waiting list for two years. When he joined the center, he was six.

4.1.3 Mothers' Suspicion regarding the cause of Their Children's Developmental Problem

I was concerned about the mothers' perception as the cause of their children's developmental problem under the first research question. From my point of view, mothers' stress is linked to their perception and belief about the cause of their children's autism. It also can be interrelated with their view to autism and coping strategies. Five participants perceived that the following could be causes for their children's autism: medical error during the delivery, genetic factors and problem during pregnancy. The remaining five mothers' reported that might be intended by God to have an autistic child. Malate also reported that she did not do anything wrong during her pregnancy. She and her fetus were very healthy during pregnancy. Though, other mothers reported their perception to the cause differ f Martha.

Seble stated that:

I gave birth at the age 14 out of marriage. My pregnancy period was full of challenge and aggravated. My family did not want to see me at their home. I went out from home during seven months of pregnancy. I started to live in street. Staying without food for consecutive days was common. Sometimes my mother brought for me food, if no one sees her. I fall down many times. I did not go early to diagnosis; she might get early surgical

procedure. I always blame myself! I am sure if it was not early pregnancy, I get proper care my daughter would have normal development.

Bethlehem reported:

My child was born after eight months of pregnancy. Besides, during the delivery, the fetus faced problem of breathing. The science also confirmed that: if oxygen could not flow adequately to the brain system, this brings a big damage to the brain system.

Abeba said:

My pregnancy in the first month was very difficult. I was not even able to eat any food. The pain was beyond my capacity. After four months I was healthy. During the delivery, there were some medical mistakes caused by the nurses that touch my child nervous system.

Meron expressed her suspicion in relation to pharmacological agent by saying that, *Unknowingly, I took contraceptive pills during my pregnancy.*

Helen expressed her suspicion in relation to genetic factor, *I think it might be genetic factor. From my cousins there are two or three children with developmental disorder.*

Galila explained,

My work condition had high exposure to hazardous chemicals, drugs and exposure to anesthetic gases. I did not know the consequence of these chemicals on pregnancy. I worked as veterinarian. There was no any accommodation and training on the potential risk of these chemicals during pregnancy. So sad!!

4.1.4 'The Lenses of Autism in the Mothers' Eye': Mothers perspective and Definition of Autism

Mothers provide an explanation by describing the process of defining their experiences through the lens of autism. For the mothers in this study, the lens of autism was a meaning-making process that shapes maternal thinking and practice. It is a framework for interoperating and acting upon experiences that arise on their long journey.

Sable recognizes and defines autism,

Autism is the most terrible disorder. It is the most challenging and incurable disorder. It is an incident that will happen to anyone without considering ethnic group, gender and economic class. Autism made my daughter to unable sense her surrounding that made me gloomy!

Gelila expressed autism

I explained as multidimensional and a nervous system disorder that makes the children to live in their own world.

Birtukan also stated that *"Autism.... took away my child from me"*

Martha statement showed that lens of autism helped her, to navigate autism mainstream context in her meaning-making process,

There are no enough words to define autism. Autism from my perspective, it's emotionally outrageous..... because of the social stigma; It made you cry" why me??"
Financially awful.....It's very challenging to raise an autistic child because you need to change your life style. Autism is a dreadful kind of disorder. Autism is all about living in

unknown world. I am living in another world. ...you know, autism let me live in unknown and new world.

For Bethlehem, the lens of autism was about reframing relationship with her autistic child.

Autism for me is being uniqueness. My child is very unique and different. Autistic children specialized on one thing. But they cannot do the simplest thing. For example, my child can fix metal things; he can open the locked door. But he cannot open his own water bottles. Autism for me is not a disorder, it is just uniqueness. The only thing the autistic children expected from us is to understand them.

To summarize, Autism has various dimensions and definitions from the lived experiences of these mothers. Life is no longer simple and spontaneous when the mothers raising children with autism, there are a lot of things taking place in this long-life journey.

4.1.5 “New Motherhood”

Mothering is a highly emotional and deep psychological process in which women continually develop close relationship and identity with their children. It is known that, the normative motherhood has joy, stress, resilience and strength in raising and rearing child. In addition to their normative motherhood, mothers of autistic child exposed to new level of mothering experience. This finding is on the “*New Motherhood*” of these mothers that has stress, challenge, joy, resilience and strength. Becoming a mother of an autistic child involves a new level of motherhood. The normative motherhood is well known and constructed. Though, “*New motherhood*” is the process of distinct routine, unknown, unpredictable and unexplored in mothers’ experience. There is no any theory,

structure and approach to explain “*new motherhood*”. Mother of children with autism explored themselves to the unknown motherhood in emotional and psychological process.

For instance, Martha visualized her parenting journey as “new motherhood”

I am just in new motherhood when it comes to Hannel. I felt like I could not relate to my son. As time goes on, relationship to my son has developed in different way from my first son. I was able to do things with my son that interested him. I was able to recognize what set him off, what calmed him down; so all in all, it was hard in the beginning but developed into something through time. He is still fairly non-verbal; it can be always difficult to understand and what his needs/wants are. Hannel tend to be alone. He is not emotionally aware of my feelings. I feel that this can be the bridge between me and my son. We have our own ways connecting and having fun with each other. This makes feel closer to him. It helps our relationship. I always try to do a pretty good job of keeping the attention equal. I always manage my time very well. Before letting him to do something, I need to think and plan how to help him. If you fall in the process of training once, you need to start again. For example; to train how to brush his teeth; I do not only tell him that “you have to brush your teeth”. Rather, first I do let him to touch toothbrush and toothpaste. This helps him to feel and sense. Teaching basic life skills takes and needs a lot of energy and time, as I experienced it.

Gelila stated her multiple role in new motherhood. In addition of being autistic child mother's, simultaneously she has been researcher, wife and mother to other siblings. She expressed her “New Motherhood “in this way,

I have become more patient and started everything from scratch. I need to be careful and focus on detail actions. My mind always ready and follow everything of his action. If I miss something, I need to go back again. I need to give my full attention to him to make if not things became worst. My day is full of tragedy. I am working mom, I am mother of two boys, I am mother of autistic child and I am a wife. When I care for my child, I do not only get tired but I feel down.

Helen expressed her new motherhood, In the way of exploring their major life experiences; having to make life style transition and her relationship and parenting with her autistic child,

I could not define my parenting style; it has always changed because his daily routine is different in each day. So, I am flexible, I could not predict his days. Life is no longer about me; it is about Henok and how I can help to make his life as easy as possible. My daily routine is surrounded by him. I get time to myself when he goes to school. His behavior is hard to deal with it. I am trying all my best to train and support him. It is necessary to be faithful. It is necessary to speak clearly and becomes tough during his care. If I have not been tolerant and provide every balance, I may experience many problems in the future. I realized early intervention and training is vital to eradicate the future burden. For example, to train his toilet routine, I and he sat for one whole day in the bath room; he ate his breakfast, lunch and dinner there. After that it was simple to go toilet all by himself. He realized the timing to use toilet.

Abeba perceived the “new motherhood” in her multiple roles,

Raising Nathan; it really tests me. I have stayed strong. I always put my child first. I usually wake up early in the morning and cook breakfast to the family. After that, I help

Nathan while he gets dressed and take him to the Bright center. Following that I do the chores. Then I bring back my son after finishing the school. I get back to house chores again and take care of him at the same time. This routine is very depressing to me; there is no time to take care of myself.

Bethlehem reported, raising autistic child became a night-mare for her. Eventually, after long process of stress and adjustment, she has begun to reconstruct the normative motherhood. Meaning that she has got to her motherhood and the ways in which they rewrite her experiences of raising a child with autism. New motherhood conveys her experiences from normative motherhood.

I have changed my parenting style to Henok .He is totally different, I have started from zero. Before I realized the issue and little things that made me upset; but through time, I have developed patience and figure out what he wants. Henok expressed his needs by crying. His cry, scream and behavior were the way to explain his needs and emotions. The autistic children need full concentration and follow-up from you. But when it comes neuro-typical children; it is not much difficult. When you become an autistic child mom, you need to be a researcher and you need to figure out everything.

As the mothers discuss the way they have begun to go forward after their children's autistic diagnosis, they haven taking various strategies to teach their children to meet the milestone of their children development. These experiences have changed their personality and their world point of view as mothers' of children with autism. The process of meeting the challenges posed by raising autistic child, the new motherhood facilitated mothers' reconsiderations of their own motherhood and their conceptualization of being mothers of children with autism. New Motherhood required reframing goals,

adjusting behaviors and developing new life skills to achieve a new mothering. Parenting in context of raising children with autism which, shaped by mothers' previous relationship and understanding motherhood. They began to articulate a different coping mechanism and learn new life skills in their long maternal journey. They started to explore diverse new life skills and perspectives to nurture their children with autism throughout the course of their lives. In the process of caring for their autistic children, these mothers continue to search for meaning of raising child with autism and questioning their new life experiences.

4.1.6 Positive Learning Experiences in Their Motherhood Journey

The study also showed that there are some emerging positive outcomes in raising a child with autism in the midst of their mothers' challenges and stress. Most of the mothers in this study described a positive learning experience in their motherhood journey with the autistic child. They also described personal benefits that would have not occurred without the presence of their child.

Martha explained,

It teaches me extreme time management/time budgeting. It teaches me lots and lots of patience and understanding, appreciating the small things in life. He teaches me emotional intelligence. It was not an easy way kind of flat curve that I bring after a lot of up and down, anger, tears and anxiety. It changes my lifestyle and direction. It also teaches me a life priority.

Gelila further said,

It makes me careful person. It also makes me more organized and programmed. I learned how to be consistence and hard worker. It gives me strong personality and solution focused person rather than focusing on problems.

Meskerem reported,

Oh, a lot, the most important thing I have learned is patience, patience and patience! This is one of the hardest life journeys to deal with; so you have to remember to be patient with your child and be calm. I also learned to be more sympathetic for such kind of children.

Samerawit said:

I have learned patience. I learned not to stop; if something goes wrong, not to always make it right immediately, not to open a way to complain. I actually learn to step back and walk away and come back again. It made me strong woman.

Despite the ongoing stress and challenges of caring for their children with autism, mothers have reported their positive experiences and resiliencies. By their mothering journey, they were able to experiences an increased patience, confidence, courage and sympathy in their maternal intuition.

4.2 Causes of Stress in Mothers of Children with Autism

The mothers reported that caring for children with autism can be all consuming which, causing adverse effect on mothers .The stress of caring for their children with autism permeated throughout their life .Mothers have faced worry ,fear ,depression and stress on raising a child with autism .

4.2.1 The Severity of Children's Behaviors

Most of the mothers reported that their children's behavioral characteristic and ways in managing their children's behaviors became more challenging and stressful for. For instance, Meron talked about her son's challenging behavior,

My child hurts himself very much; he bangs with a wall and floor. He scratches and pinches himself and me; I still have scars on my hands. He shouts in a wired voice. I think these kinds of behavior and actions because of he is nonverbal and he failed to express his feelings. He is very restless. It's very challenging and stressful to raise such kind of child.

Abeba further talked about her son unpredictable behavior that let her to feel overwhelmed,

Initially, I did not rule that out for quite some time but the expectations changed drastically. Its long process for that happen, it does not happen overnight. The expectations change at first pretty frequently and then later on kind an annual bias. I cannot predict his behavior that makes me overwhelmed. He sometimes has good toilet routine and sometimes he does not. It caused extra burden and stress on my life.

4.2.2 Uncertainty about the Future Concern of Their Child

The mothers recognized that their child may not have a future that most healthy children will have such as future caring, marriage and university studies. The participants' realization that their child will not lead a normal life contributed for their stress and anxiety about the future. They are preoccupied with thoughts of uncertainty.

Seble also explained that she feels hopeless and make her down and stressful by saying,

Though, when I got pregnant with Selam, I was 14. Due to our narrow age difference, we became friends now. But the reality it just a dream! I was eager to have someone by my side now as friend and as daughter. She is now 17, but she cannot sense and realize her own world. She does not know what is going on now and near future. She might not get her soul mate. She might not join university. These make me sad! I am terrified when I thought what is going to happen to her if I am not longer around her. I do not have anyone to relay on. Sometimes I wish two of us die with accident together. It frustrates me when she is in deep sleep; I could not be sure to see her in the next morning.

Samerawit Said,

My main concern is what will happen to him when I am not around anymore.

Gelila stated,

I do not know what to hope for my son's future. Sometimes I pray that God takes him before me because I know that no one could understand and take care of him.

Some of the mothers also reported they had to redefine their hopes and dreams about their child's future, though the journey became challenging for them. They said that they will struggle to the end to let their children to function well and make their future bright.

Bethlehem showed that she has no fears for the future .She focused on the planning which is fundamental in her child.

I have no fears about the future. My only goal is to have him recovered. The most important is that he becomes self-sufficient. I always try to make him sustain his life by himself. I believe God will help me to go through this. God will make things alright. I am praying a lot.

Helen also said she was doing her best to prepare for the unknown.

The most important thing for me is to lead him on the right way. I am trying to make him-sustaining. Hopefully he will do that!

4.2.3 Children's Inability to express their Feelings and Needs

All mothers reported that their children's inability to express their feelings and needs aggravated their stress. Most of the mothers thought their children may be exposed to various abuses. Their children cannot report about their feelings. As result, mothers figure out the one of the causes of their stress is their children inability to express their needs and feeling. For instance,

Seble talked about her fear to her daughter by saying,

My daughter is currently 17. She has started menstrual cycle. The time is not good. She might have a chance to be exposed to abuse and sexual violence. Since, she is unable to express her feeling; I am much stressed what happen if something happens to my daughter; I always figure out her emotions, feelings and needs. I get obsessed in everything. I felt insecure.

Samerawit reported,

He is non-verbal; he cannot express his feelings that make me sad. It makes my life stressful. I worried about his situation. If someone bit and abuse him; he cannot help himself. My eyes always follow my child. My mind always researches about his situation. It's really stressful!! There is no anything that makes me feel comfortable.

Martha expressed,

Because, he still fairly non-verbal. It can be always difficult to understand his needs and wants.

Samerawit also explained her experience by saying,

The biggest challenge for me is that he hides his feeling; if he gets starved, he keeps silent; and if someone abuses him, he could not tell us. That makes me frustrated.

Mothers also found out that it's really difficult to access any kind of treatment, education and support. Nearly all mothers mentioned how difficult it is to find education, treatment and other support for their children. This led to manifestation of the fourth theme: difficulty finding education, treatment and support for their child.

4.2.4 Inadequate Service

Most mothers stated challenges related to finding schools, treatment, receiving information for services and therapies. Many mothers reported that occupational therapy, speech therapy and Applied Behavioral Analysis (ABA) recommended for autistic children, but the reality is that these services are scarcely available and inaccessible in Ethiopia. Mothers also said that they received limited information about the course of the disease (prognosis): what to expect as their child continues to develop and age.

Most participants identified that their child's doctor had limited knowledge or information about autism. The mothers discussed their challenges and efforts towards understanding the problem. Getting accurate diagnosis or knowing what to do for their child were very challenging for almost all mother.

Bethlehem remembered the situation,

I did not get help from the medical aspect. There was no any psychological and medical support during and after the diagnosis. I experienced the worst thing in raising autistic child.

The mothers also described about their experiences with schools and teachers who were not well trained or experienced about working with children with ASD. Some of these participants experienced difficulties in finding appropriate schools for their children.

Martha stated,

There is no inclusive school. There is no a well-trained psychologist, therapist in our country, the government does not consider this kind of relevant issue. Most of medical stuffs are not still aware about autism. My child is nonverbal; so he needs to get speech therapy. For autism there are critical times. If you could train the autistic child at age four and five; you can make their future life easier. I stressed more to make his future life better.

Gelila said,

Despite my son reaching the age he should start school; no school offered him a place. I could not find any school for those with intellectual disabilities and speech impairment around Hawassa. Before some years ago, he joined special needs school.

Most mothers reported that it's difficult to access education and treatment for their children with autism. There is limited amount of treatment in Ethiopia specifically speech therapy. Most mothers said that they could not afford the expense of the treatment and treatments are not available in Ethiopia. These explanations of the mothers raised another theme: financial difficulty in raising an autistic child aggravated their stress.

4.2.5 Financial Difficulty

High costs related to food, transportation and house rent are the major financial burdens posed as the result of autism. Most of mothers reported the financial burden of raising autistic child is very challenging and put extra burden in their life.

Birtukan explained her experiences in relation to financial difficulty by saying, *I am employee at public health center as cleaner; I earn income on monthly basis. My income is not sufficient to fulfill basic needs of my son. My husband is physically disabled and he could not actively participate in labor market. I am the one who are carrying all burden of the family. That is very stressful for me. We are living in one room of Keble house. My child wants to play freely in his home, but he could not; I cannot let him to play outside because other children do not want to play with him. Sometimes he gets angry; I cannot afford to rent a house that let my child play freely.*

Meron identified financial factors as her most significant source of stress in her efforts to treat her child, *I and my husband are not getting enough amount of money. My husband's work is temporary. There is a transportation cost for sending a child to school. The house rent also poses the main financial burden. We are living in small room; I could not teach my son toilet routine, since we do not have a place for that.*

Participants also stated financial burdens in provision of balanced diet. Because the cost of food items is high; they are unable to feed their children as expected. Samerawit explained her experience in the following manner. She says: *My son always wants to have special and delicious meal. If the meal served is not well prepared and delicious, he refuses to eat. He likes to eat meat and various fruits. I could*

not provide balanced diet and, hence, unable to meet the need of my son. As mother that makes me sad.

Gelila explained,

For my son, because of the food allergy and all the medical conditions, I have to cook almost everything for him. After work, I spend my time on shopping and cooking. I have cut back on the numbers of hours. Sometimes I get to work lately.

Two mothers said they left their job to care for their children. According to Helen,

When he got diagnosed, I quit my job. I stayed home just to be with him full time. Since then I have not gone back to work. So, we are single income family. It has financial burden. And I would love to go back to work but I know I cannot. It just would not be feasible right now with all his needs.

Seble also said,

I wish to engage in income generating activity. But my daughter requires more care and attention. I could not rely on her step-father. That makes feel insecure!

The participants were asked about other supportive system. Most of mothers reported they do not have any supportive system to rely on. They do not have enough time to care for themselves as they give priority for their children. These led them to experiences anxiety, worries and stress.

4.2.6 Lack of Self Care

Through the interview, the mothers stated that they often put their children's need ahead of theirs, sometimes to the point of putting their own health at risk. The mothers consistently spoke of the amount of time and energy they devote to care of their children. This takes all the time and energy and they abandon caring for themselves. They talked

about not getting adequate sleep and withdrawal from any kind of gathering and things that they used to love to do.

Abeba described her experience when her son was more difficult to handle and no other family member was willing to care for him. During this time, Self-care was not a priority.

His siblings are not supportive. My husband is busy with his work. I cannot even get an hour away. Like I had to keep him with me where ever I go and what I ever do. I feel very sad when his siblings fight with him. At first I thought because they were young and they might not be aware. As time passes, things do not change and getting worse instead. This makes me sad, and at the same time it makes me nervous. He might show big progress if they were helpful to me. But the truth is, they are not interested to support their brother. I am the one who has carried the burden. There is literally nothing I could do by myself for years.

Martha said,

At the beginning, I was not myself; I withdraw from things that I used to love to do. I did not give much time to myself. I was very sleepless. It is very hard if I do not get support.

Mothers identified lack of support from the immediate, extended family members; schools, professionals, and general community make their life more challenging. Mothers reported that caring for a child with ASD often has a significant impact on the mothers' life with disrupted routines, financial difficulties and a strain of personal care. This needs supportive community.

4.2.7 Social Stigma

Most of mothers in this study reported they are experiencing stress, because the community's reaction towards to their children. They said that the society expose them to experience social stigma and embarrassment associated with inappropriate behavior displayed by their children. Most of them express their situation in this way,

Meskerem said,

The culture is that everybody believes since he is not physically disabled, he should be he is not doing it right. They look down at you like maybe you didn't train him or he is a spoilt child. They do not know what is all about autism. When we went by taxi, people see it as bad behavior; they see me as that woman with the badly behaved child.

Martha says,

The community members are not aware at all. There is big stigmatization. The community around us shows false sympathy rather than giving support and love to Hannel. It sometimes discourages me. The community perceives autism results from evil spirit or they believe that there is curse in family. My family also did have the same perspective like other community member till they really understand the issue. I thought that my families were well educated so they could easily accept but they perceived it negatively. Now, they become supportive for me and my son. We are the reflection of the society regardless of the level of education we have.

Seble allocated,

It's very hard to go outside, as I never know what will trigger my daughter outburst. The looks, comments, and eye rolls from the public has been the usual way of life. Everybody (almost) just assumes you are bad mother that avoid certain activities or outings because

it is just too hard. People stare and make rude comments; when we went to her school ...we saw the tune of everyone out.....the insultIts hard!! , it can be extremely embarrassing...who can I rely onThat can care of my child...my family or community. I cannot trust and love the community. You know what.... It makes me sick.....the community is one of the headache. I always host horrible feelings and I feel like I am constantly defending my daughter and myself..... the reality is that it's no one's business.

Birtukan reported,

You have the deep cultural misconception; we have a really stigmatizing society where most of mothers hide their children because they do not want anybody to know. In my neighborhood people start avoiding me, people start gossiping on me. I feel helpless and I get tired of everything.

However, Bethlehem believed in awareness creation. Despite, it is contention of stigma that the community towards children with autism .This was not because they are malicious, but they are lack of knowledge regarding autism issue .Availability of information that affect individuals with autism may help people without knowledge to change their stance .However; their stigma can only change if it was genuinely. She expressed her experiences by saying,

Most people viewed that he is a spoiled boy. Since I have a boy who requires more attention, my participation in social life is limited .Most of the time, they do not expect me to attend funeral, birthday parties and wedding ceremony as they understand my situation .When you go to public areas and hospital, people show you false sympathetic gesture. The society can understand if we teach them about autism. Most of

the time people relate autism with evil spirit; they also thought it as mental illness. The societal understanding might hurt us. Mothers raising an autistic child ought to create awareness about autism

The mothers also reported that they experience a lack of social support when it comes to their child with autism. Some participants experience a lack of understanding and support from their family members and general community.

Abeba explained,

My neighbors and member of the society don't understand my child situation. My neighbors knew about the medical mistakes during the delivery; but they said, "she is sinful and her child became like this". The stigma in society makes me sick. When I go everywhere, I talk about the issue of autism. I always try to create and increase the societal awareness about autism. Even my sisters could not understand me. I and my son always went to church, birthday party and social gathering, because I want to let him to adapt his surroundings and to discover his environment. He goes to Sabbath school every time in church.

Helen also said,

I have had very little support and understanding from friends and/or family. A lot of people think they can fix your child problem, nobody really knows what it is like 24 hours a day. No one ever try to understand your situation. They tend to judge you and to manipulate you.

Two participants identified that a typical belief among the Ethiopian society is that ASD or developmental disorders are spiritual problems or of a supernatural cause. Participants identified difficulties at church.

Gelila said,

I faced most challenges in church. The church community that comes to me and say “sister, you should pray a bit more You need to kneel down. God will purify you and your family from your sin.” People feel embarrassed when they are around him. Now days, I isolate myself from any kind of social gathering, because my boy always creates destruction and mess. I preferred to stay away from any kind of issues.

Bethlehem expressed her experiences,

For me the biggest challenges resided in church. The experience with the church is that most parents do not want to sit beside me and they start looking at us as we have done something wrong. Our culture does not accept autism. We see it as demonic; we see it as evil. Some are still praying against it. When I try to tell them that my child is autistic, they say: “what is autism? Why are you accepting that? He is not autistic, God forbid!”

This research found out that mothers who have a child with autism need more support from general community. It is important to mothers that the general public becomes more educated on the topic of autism. Bethlehem wants “They, Community Members, become more educated, research autism!’. Most mothers raised the issue of community awareness in the line of social stigma. Mothers are most likely looking for more support from the community so that they no longer feel embarrassed when they need to bring their child with autism out in public. If the community were more educated on the topic of autism, and were more supportive, mothers might feel more empowered and eager to work on behaviors in the community instead of avoiding outing all together.

Regardless of the unclear path of autism in medical context of our country and uncertainty regarding the community reaction, lack of support, treatment and

information; the mothers identified coping strategies and supports can help strengthen mothers' resilience against stress over time which are discussed with the researcher under the third research question.

4.3 Major Coping Strategies and Support Used by the Mothers' to Strengthen Their Resilience against Stress

The stressors posed by raising autistic child placed mothers, on guard the possibility of losing piece of their self and their children. In keeping things well as person, mothers utilized different coping strategies to remedy and strengthen their resilience against stress.

4.3.1 Religion

The most utilized coping strategy, reported by all mothers, was religion. Some of the mothers' stated that they engaged in spiritual activities .They used spiritual healing methods such as holy water and prayer to their children and themselves to cope up from their stress.

For example, Meskerem said,

I always hold hope and accept everything for my son. I need to accept it. I always go to church and consult the priest. I always get relief when I go to church. I also take my son to church; have a prayer for him with the priests until now. He is a gift from God. I call God to strengthen me. I ask for patience.

Bethlehem also said,

Sometimes I locked down myself and prayed a lot. I asked God to give me strength. My child will join heavenly kingdom because he does not know about sin. Most community of church members said to me, "Please, keep your son at home, and do not bring him at

church". I always said God needs my son's worship. We always went to church with my son.

Meron expressed her religious coping,

I always go to church and pray a lot. 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. My son tries to sing songs. He gives his own worship to God. This gives me relief. I believe in one thing God is always right in my life and my son's life too.

Gelila also said,

I kneel down and pray a lot, when I get burnout. I cry a lot and keep praying. I believe that God is my father and he will not leave me alone.

In line with religious coping, some of the mothers mentioned that it was important to get support from their immediate or extended family, friends and community members to cope up from their stress which led to the emergence of the second sub- theme under the third question: social support.

4.3.2 Social Support

Mothers reported that using informal support network from family, friends and baby-sitter or home maid helping them to take time off from mothering duties. Most of the mothers said that proactive help seeking behaviors and supports enable them to remain positive and optimistic.

Meskerem express how her mother's support helped her too went to all these by saying,

My mom let move in with her when I needed the most support and helped my son. Besides my mom, my husband is very helpful to me.

Martha said,

My husband was a great supporter for me. Maybe he is stronger than me! Yes, He is, I admit! When I was frustrated, he was always there next to me and got my back. My husband is very supportive and responsible. He taught me about autism. He is with me with this long journey. We share the burdens of raising Hannel together. I always feel that I am not alone. Besides, everybody in family especially my sisters have always been more than willing to lend a helping hand in care of our son when it's needed. They have always been up beat, positive and extremely supportive. I would not say that I was ever embarrassed by my son's behaviors. I know that when he would have meltdowns it would be exhausting for us, but I think we had a good support system around me.

Most of participants mentioned that psychosocial support from Joy and Bright autism centers has a great contribution for their children and mothers life. All mothers identified that the centers are enabling their children to show visible changes that give for mothers a great sense of confidence to hope for their children's future. It creates an opportunity to meet and play with children with same condition. The two centers arrange monthly meeting and training for parents, having autistic children, that has greatest input to the life of the mothers.

The participants expressed the monthly parent conference as enabling environment and always inspire them to dig out things for their children better future. They said they use parent meeting day as the main source of psychosocial support. They expressed the parent meeting day as follow,

Gelila said,

I perceived parent meeting day as big day. It is big platform to my life. I feel like some people stand beside me to hear my voice and to share my experiences. I always feel there is someone who can hear me. It gives a great sense of confidence .Talking is greatest cure!

Martha said,

Meeting with other mothers; it is really supportive because I have someone who listen me. We share some coping mechanism and experience. It is a big support system. Getting this kind of support made my life easier.

Abeba also allocated,

It gives us the opportunity to share our experience. Most of the parents are waiting anxiously because it offers us relief and it cures us. We are family.

Bethlehem expressed the contribution of the center,

After he joins the center, my son is showing progress. He is developing self-helping skills. He can feed himself; He can brush his teeth, dress up by himself. He can help himself in the toilet. He is trying to figure out English letter even though most of the time he missed them. He also tried to write.

In the line of social support some of the mothers mentioned that it is important to be up-to-date and be educated about the facts regarding their child's condition. It helps them to strengthen their resilience against stress which led to the third sub-theme under the third research question which is actively seeking information about autism and its intervention.

4.3.3 “Learning All You Can”

Some participants said that they always actively seek information and treatment for autism. They tend to educate themselves about autism. This approach is helping them to develop and maintain their sense of empowerment, problem solving skills, and self-efficacy and reduce their stress. Moreover, their new motherhood as multifaceted roles well beyond the typical maternal experiences which, took their effort to provide their children with the most efficacious training and treatment. As mother, researcher and therapist, participants found their coping strategies revolved nearly exclusively around researching, selecting and securing treatments and treatment approach.

Helen shared the following,

I read a lot about autism, I read many research, books and articles related to autism. My reading helped me how to train my son about basic life skills. For example: how to train toilet use, how to eat properly, how to dress by himself and so on. When I read more, it minimizes my burden. It also helped me how to handle my son's behavior. The fact and exposure that I get in my reading time helped me to accept my son's developmental problem. When I became an autistic child mom, I need to be researcher and I need to figure out everything.

Gelila also said,

When I read more, it gives me a relief. When you raise autistic child, you need to learn all you can. I read more about the treatment on internet. My reading time is road map for me. It gives me direction to deal with my child. I always read. I know that I can make my child future better.

Martha expressed by saying,

I read more.' I learn all I can. I spend these times by finding solution and researching about the issue. I love to spend my time by finding solution, to make myself emotionally stable. This helps me to accept my child as he is.

In regarding of all these, when they move to all these experiences, mothers tend to accept their children's condition and trying to appreciate each little progress which led to the emergence of the fourth sub-theme under the third research question which is Acceptance and Encouraging any progress the child achieve.

4.3.4 Acceptance and Cherishing Little Progress

Most of the participant stated the process of acceptance and normalization which took many times and happened in slower process. This process enables the mothers to view autism in its positive way. It also simplifies their ability to cope up from their stressful life that give them a greatest insight to appreciate and acknowledge each progress that child achieve through time. All these brought to them happiness and enable them to enjoy each little thing in life.

Helen found acceptance and appreciating little progress to be long and slow process. She reported,

From the diagnosis and onward, I just said that is enough of that grieving thing, I guess I got a lot of work to do. So, that was a big turning point for me. So, then I start to see the bright thing at the back of the darkness of autism, I start to cherishing my child progress, when he is doing things independently, when he washes his hands, he uses toilet by himself. Now I am very thankful by his progress.

Martha has same thought of acceptance like Helen; she also expressed the way how she accepts it by saying,

Oh, right away. It's a kind of hard not to accept that. I mean my child is drastically different from others. I always hold put for something different to happen but I still need to accept my child for who is, no matter what the circumstance may be. I never was embarrassed at all about his behaviors, because he is my son; now it's is just for me to have an autistic son, so I am always used on this way. I was not embarrassed to take him in public area because he is my son, I cannot help it! So, if people have a problem with it in public, that's their own fault. I do not give piece about what some persons think about it. My child is my priority. If they do not love and care about my son.

Bethlehem also said that when she accepts her child situation that bring a lot in her life by saying,

I started to train him basic life skills that he needs to acquire at his age with God help; I opened these Bright Autism Center in Hawassa. I am always optimistic. I realized that raising an autistic child has changed my life and my family dynamics. But it does not always mean in negative way. My child teaches me a lot about life, he makes me a stronger person. It is life changing and has hard at times. But I allow myself to see the good spirits my child has. When I get frustrated, I remember that my child way of learning and thinking is different from my own since, he is unique and special. I am very strong and God helps me to get strength. When I accept my child's situation, it gives me strength, pave me away to be creative. Now, I am very happy to see my child when he lives by his own world.... It's okay!

Meskerem found that accepting and appreciating little progress that her child made was slower process. She said,

To be honest, it really took time for me to accept it! It was very hard journey. I feel it slowly happened with researching and spending more time with my son, but I have always been accepting, you know that is big reality which stand in front of me ...what can I do then? I just accept it!! Believing that God makes no mistakes and every person on this world has a divine purpose ease some of the worry and frustration that this diagnosis has brought about in me. My child always makes me laugh and he is the best thing that happens in my life.

Seble reported being glad that her child is making improvement but still dwells on things she is unable to do. Seble still has not fully accepted it. She stated,

I still have not found acceptance, at this point. I do not know if I ever will because I feel that at every point of her life.

The process of acceptance and appreciating little progress a child makes over time enable mothers to experience a shift in maternal thinking and practice. They reframed their goals and expectations with the regard to their children's world view. By engaging in the world view of their children, mothers were able to experience profound joy in their little achievement. In the mother's stories of how their bond with their child has shaped their world view, the sub- themes of Focusing on Positives emerged.

4.3.5 Focusing on Positives

Mothers described how the relationship with their autistic child differs from the relationship that they observe in typical families and even how it differs from their relationship with their own neuro-typical children. That is, the experiences of linked live

extends beyond the nature of relationship to shape mother's meaning-making process and provide a distinct orienting context for negotiating the world.

Bethlehem shared her experiences by saying,

My child is very unique. I am very proud of him! He is different because he is not looking and viewing situations in normal context. He senses and perceives that the world in different way. That is amazing!! My son let me to experience the thing beyond the horizon; our relationship is unique and different. As mother I just need to understand things based on his view. That is his point!

Samerawit demonstrates the intersection of mindfulness and enabling develop her in new motherhood,

My sons can nonsense talk now. He talks non-stop. I spent years and lot of money trying to find solution, I am just so grateful.

Martha also said,

My son is in his own little world, happy and friendly. He puts life into perspective makes you think why cannot, we all just by pass the stresses in life and be happy with the simple things in life, just be content with what he has.

Gelila story makes evident this mindfulness in her story of linked lives by saying,

Now I just enjoy and acknowledge the relationship between me and my son, just spending time together, viewing about emotion and feelings and trying to communicate. My boy understands and view things in different way. When he want to see and take something, he just make it up-side-down, you know that is the way how he visualize it .It is more about my understanding and quality of our relationship. It is not so much getting from

one point and to other point. I am not trying to get to each milestone steps. We are enjoying the moment .He let me in his world, new perspective and new insight!

4.4 Interrelation Themes

Results showed that the experiences of raising a child have profound influence on the mothers of children with autism. Most the themes are intertwined each other's in the findings. For example, under the first theme, sadness, despair and feelings of being overwhelmed as reaction by mothers was due to of lack of information and psychological support during and after the diagnosis .Most of the mothers exposed to drastic stressful life journey because they could not access treatment, education and information about autism, which let them to do not articulate the severity autism which led them to worry about child future. Lack of social support and limited availability of resources made the life of the mothers more complicated in Ethiopia. This maternal experiences in context of raising children with autism brought new motherhood that shaped by mothers' relationships with their children, experiences and understanding of the new motherhood and other related situation. Despite the worst situation, mothers are developing their own coping strategies which strengthen their resilience against stress. Thus, the mothers' engaged in religious coping mechanism such as prayer and participating in church, then mothers continue to educate themselves about autism which help them to normalize and accept the situation of their children as well as appreciating and encouraging all little things that child achieve. This also lead them to view the world in different way the state of mindfulness and focusing on positives that shapes mothers meaning making, re-conceptualization to understand their own context in their journey of raising a child with autism.

5. CHAPTER FIVE: DISCUSSION

In this section the researcher interprets the major finding of the study. These findings are discussed in the light of the research question, related studies and theoretical framework. The finding is discussed under three main themes.

5.1 The Major Experiences of Mothers' during and After Their Children's Diagnosis

As the finding revealed in terms of how mothers reacted to first learning of their child diagnosis, it was found that mothers' similarly experienced feelings ranging from sadness, despair, and feeling of being overwhelmed as reaction by mothers. This research finding is consistent with many studies that conducted on the area of autism across the world. Thus, most research found out feeling of grief, sorrow, shock, confusion and loss by parents when they informed of their children diagnosed with autism (Sigel,1997; Paul,2001;Avidet.*al.*,2000;Alitiere,2006;Bayat,2007;Osborne&Reed,2008;Lori,2008;Joachim and Roberta,2012;Ashely,2012;Lindsey&Roberta,2013;Angela,2013).

The finding specified about the mothers' prior knowledge about autism before the diagnosis. All mothers reported that they knew little before the diagnosis. This lack of knowledge contributed for the mothers feeling of being overwhelmed, despair and sadness during the diagnosis. Equally to this study (Lindsey and Roberta,2013; Nafiseh *et al*; Ashely,2012;Anthony ,2009; Paul ,2001) found out that most parents with autistic child have limited awareness of autism that led to initial reaction of denial ,fear and shock during the diagnosis.

All of the mothers' in this study indicated that they received very little psychological support and guidance from pediatricians. The participants of this study highlighted that there is a knowledge gap among general medical practitioners. Most mothers reported that this barrier in treatment and services seeking journey made their life more stressful.

This finding coincides with studies of (Mung'ala-Odera, Newton and Hartley, 2010; Igwe *et al.* 2011; Joachim and Robert, 2012; Esegbe *et al.*, 2015) that found parents being displeased by the limited information and services that they got during diagnosis. Further Bello-Mojeed, Bakare and Munir (2013), stated that this lack of information and services during diagnosis contributed to the challenges they encountered in finding treatment, services and schools for their autistic children.

The finding about mothers' suspicions regarding the cause of their children developmental disorder, three mothers thought that to have an autistic child is intended by God. This finding is consistent with the findings of Cherent and Opdal, (2007) which displays most of the parents in their study attributed the cause of the children's intellectual disability to God.

However, five of participant reported that genetic inheritance, labor complication during delivery and environmental factor as cause of to have autistic children. This finding similar with (Sonya, 2006; Altieri, 2006; Johnson and Myers, 2007; Russell & Norwich, 2011; Simonoff, 2012) where the explanation about the cause of autism links have been traced between genetic and environmental factor. These include genetic inheritance, labor complications, problematic infant immunization, and viral infection during pregnancy, head trauma and organic defect in the brain as causes for autism.

Furthermore, two mothers also demonstrated that the cause might be lack of quality prenatal care and experience some illness and complication during pregnancy. The finding of Anthony (2006) supports the idea by mentioning that mothers attributed the cause to have autistic children to lack of quality prenatal care and experiencing illness during pregnancy.

This finding also contrast with Gona, Mung'ala-Odera, Newton, and Hartley (2010) study, which stated that parents reported the disability of their children is associated with evil spirits and punishment from God .Moreover, Joachim and Robert (2012) finding is contradicts with the current finding of this study, by stating that parents demonstrated that the cause of to have child with autism in relation with witchcraft and traditional taboos.

The finding with regard to Lens of Autism in mothers eyes. Most mothers define autism based on the framework for assessing and characterizing the role of raising autistic child in various relationships in their lives. Thus, nine mothers define autism as challenging disorder that let their autistic children and themselves to live in the new world. This finding of the study relates with Algozzine *et al.* (2004) defined autism as severe disability that has intense lifelong effects on the diagnosed individual and their family. However, one mother defines autism as “uniqueness and difference”. There is no literature that, specifically define autism as uniqueness and difference.

The result under “*New Motherhood*”, mothers in this study reported that raising an autistic child brought new parenting. All mothers described that their journey let them to change their life style, change the family dynamic and their relationship with their autistic children. The “*New Motherhood*” enabled mothers to explore new life skills and

to manage their multiple roles. Similarly, Woodgate et.al. (2008) discovered that parenting a child with autism had similar experiences in this study. Parents in the Woodgate *et al.*'s study demonstrated that, they were on their own world for all aspects of daily living and challenges of parenting child with autism. Furthermore, Mackey and Goddard (2006) also found that parenting a child with intellectual disabilities described as parenting of being their own.

Despite the challenges that mothers faced in parenting a child with autism, it was the child that gave them positive learning experiences to continue on in life. In this finding, mothers were able to regain a sense of control over their life. Thus; resilience became more evident in this finding. They described their child's positive contribution to their long journey such as; patience, industriousness, appreciating little things in life, redefining their priorities in life and being sympathetic for other people. Consistently, (Bayat, 2007;Woodgate *et.al*;2008 and Angela,2013) parents in these study found that patience, redefining their priorities, appreciating little victories in life and being sympathetic for other people .Specifically ,mothers in this study mentioned patience. Learning patience was essential to the survival of parenting a child with autism in this study. For parents in Cashin's (2004) study, parents believed that the development of patience was one of the positive learning experiences. However, there is no any literature specifically looking at the importance of industriousness in parenting child with autism.

5.2 Causes of Stress in Mothers' of Children with Autism

The finding revealed that caring for children with autism can be all consuming that, causing adverse effect on mothers. Moreover, the stress of caring for their children

with autism permeated throughout their lives. These mothers have faced worry, fear, depression and stress on raising an autistic child.

This study found out that mother's face strain related to the severity of their children behavior. Mothers mentioned behavioral issues, bad temper, screaming and physical violence toward themselves and others. This made mothers to face extreme challenges daily in dealing with behavioral problems.

This is similar with several studies such as (Gray, 2002; Bello-Mojed *et.al.* 2013; Aadil *et.al.* 2014) stated that parents distressed because of their children challenging behaviors. Furthermore, (Abbeduto *et al.*, .2004) found out that most consistent predictor of maternal stress was their children's behavioral difficulties.

The finding regard to uncertainty about their children's future brought permanent worry about their children. Eight Mothers' reported that they worried about their children future. These mothers were highly concerned with their children's future, ability to be independent, healthy and safe. Similarly (Paul,2001;Gray,2002;Bayat,2007;Angela,2013 and Aadil *et.al.* ,2014) found out that permanency of their children condition, their children level of dependence as well as what the future hold for their children as a great sources of stress for parents. However, two mothers in this study demonstrated that they have no fears for future. They focused on planning which is fundamental in the ability for their children future. They reported that they are doing their best to prepare for unknown and the unexpected. Parental concerns for their future of children are documented in the literature (Green, 2003; Vickers &Parris, 2005; Murphy *et al.*, 2006; MacDonald &Callery, 2007)parents embraced their child with all their strengths and weaknesses, cherished the little things, planned for present and prepared for the future.

The study discovered that most consistent predictor of stress for mothers is children's inability to express their feelings and needs. All mothers reported that they have fears that their children might subject to abuse and neglect due to their children's unable to express their feelings and needs. Similarly (Audu & Egbochuku, 2010; Egbochuku & Imoitseme, 2012) stated that individuals with mental disabilities are subject to abuse, neglect, isolation as well as poor support and treatment.

The finding revealed that inadequate services and support aggravate the mothers stress. Many participants reported that lack of ASD services in Ethiopia. Participants described experiencing challenges in finding ASD intervention services and schools. Services were nonexistent, too far away, not accessible or available. Four mothers articulated that they relocated to different city where there was an ASD treatment services, and they couldn't access the services.

Most of the participants described dissatisfaction for the poorly –trained pediatricians that deal with their children situation. Some of the participant experienced challenges due to lack of availability of speech therapists. They also faced long wait lists. Four mothers expressed that they embarked on intervention based on the information they read from the internet. One mother reported that there was no early intervention available, and as result she trained herself to provide services to her child. This finding is consistent with (Alem, 1997; Alem, 2000; WHO, 2006; Shibre *et al.*, 2008) suggested, that inadequate medical services, social services and lack of government support are some reasons that aggravated parental stress. According to Bronfenbrenner (1997), an individual's experiences and development can be indirectly impacted by formal and informal organizational activities occurring in the individual's primary dwelling. The

organization at Exosystem level includes government agencies, healthcare centers and schools. Participants in this study explained that they were influenced by the challenges with health care professionals, schools, lack of well-trained therapist and lack of governmental programs and support for autism. This finding is consistent with the ecological system theory the interactions of mothers with these formal and informal programs in their environment. This influenced their experiences and behaviors as mothers with autistic children.

This study also found out those mothers of children with autism experience psychological distress. All participants, regardless of socioeconomic status, described a significant financial burden associated with raising a child with autism. This includes the cost of providing for the child's needs and transportation cost. Two participants emphasized the prices for special diet items needed by child were extremely high. The work force was another area of concern related to financial burden reported by mothers. Most mothers reported that they had to rearrange their work or change and quite their job, due to the high demands of parenting a child with autism. This brought financial burden to the family. Similarly (Sen and Yurtsever, 2007; Nwanze, 2012) found that parents caring for a child with disabilities had to quite or change their job, to meet the needs of their child. Unfortunately, quitting or changing job was difficult decision in time of increasing costs due to caring for their child with disabilities.

As per finding of this study the Lack of self-care of the mothers related to their stress. Mothers reported that they have played every role for their autistic child. They are fulfilling the day to day needs of their children as well as their family needs. As result they acquired multiple roles within their home. Mothers also became primary caregiver,

wife, advocator and teacher. Mothers in this study demonstrated that, they put even more energy into ensuring their children's needs while putting their own needs a side. Mothers own self-care and necessities was placed a side on multiple role due to excessive time spent with their autistic children .Mothers dedicated their life to their children, which led to increased challenges such as lack of self-care, they could not participate to any kind of social gathering and they don't have time for leisure. These made their life more stressful. Likewise (Vickers&Parris, 2005; Murphy *et al.*, 2006; MacDonald &Callery, 2007) documented that the nature of parents of children with disabilities to focus on their child's health and needs while putting their own needs aside.

Mothers also reported that they lived moment to moment and relied on routines to meet the demands of daily life with autism as well as their family. All participants demonstrated that they tended to withdrawal from social life and things that they used to, these make their life more stressful .Correspondingly (DeGrace, 2004) studied that parents prioritize their child needs ahead of their own and doing everything they could to provide the best life for their child. Additionally, (McKay and Goddard, 2006) found that due to the increased work involved in taking care of child with intellectual disabilities, there focus on the child health rather than the parents' own health.

Most participant in this study identified common belief in the Ethiopian culture. This common belief influenced the community reaction to the mothers or children with autism. Mothers described that the typical belief among the society is that autism resulted from supernatural problem. Participants demonstrated that they experienced various challenges and poor acceptance from different member of society including church, neighborhood, family and friends. Multiple studies are consistent with the current finding

such as (Ajuwon & Brown,2012 ;Audu&Egbochuku,2010;Angela ,2013 ;Joachim &Robert,2012:Bakere et al.,2009;Eseigbe et al.,2015;Aadil *et al.*,2014). Similarly, (Lewi, 2009; Getenet *et al.*, 2013 and Aynalem, 2014) found that challenges to autism and related developmental disabilities created by negative beliefs and attitude towards people with developmental disability.

Mothers also described lack of knowledge and understanding from the society contributed to social stigma. Because one cannot see autism on the outside, the child was expected to behave in a certain way. Difficulties, frustrations and stigmatism arose when the child with autism acted out of expectation. Likewise, (Cashin, 2004; Glass, 2001; Gray, 2002) presented that difficulties included embarrassment in social setting, hostile reaction from public when the child behaved inappropriately. As result, parents host feelings of being judged by others based on their child action. Due to the child's normal physical appearance, autism appears invisible to the public .Therefore, any undesired behavior may be viewed to be a reflection of bad parenting rather than that of the disability .Gray (2002) explained how the normal appearance by a child with autism, combined with the lack of knowledge from society increased the incidents of hostile remarks to parents, in regards to any unwanted and inappropriate behavior from their child. In Gray's studies (2002), the invisibility of autism associated with increased stress in families. All mothers in this study recommended that increasing the public awareness is vital to reduce stigmatization. Gray (2002) also concluded that increasing public awareness of autism may reduce the stigma attached to parents and their children with autism.

Similarly, activities at the macro system level of the environment such as cultural practices, beliefs, attitudes and customs, affect the individual's development and functioning (Bronfenbrenner, 1997). At this level of the ecological system the major events identified by most participants as significantly influencing their life. Poor understanding and typical belief about autism in the culture has significant impact on mothers' experiences and journey.

5.3 Major Coping strategies Used by Mothers' to strengthen Their Resilience against Stress

The stressors posed by raising autistic child placed mothers, on guard the possibility of losing piece of their self and their children. In keeping things well as person, mothers utilized different coping strategies to remedy and strengthen their resilience against stress.

The participant in this study used their spirituality as coping method. All participants talked about their spirituality as a source of their strength. These mothers reflected that Spirituality and faith in God is the bedrock of their strength, and not something that they to turn to or renew when they discovered their children's situation. Similarly, Durban et.al (2012) indicated that most parents use religion as coping mechanism which can provide them strength while they encounter various challenges of taking care of their autistic children .As reported in Gray (2003) and Thwala *et al.*, (2015) solace in God was and continues to be one of the most powerful means of support parents' who raising autistic children utilize.

Participants also discovered that they get resilient due to God's support. Most mothers believe that autism is come due to predetermined God's plan. Hence; they

cultivated their expectation from God. Consistently, Bashir, Khurisd and Qardi (2014) explore that religious faith as parameter for enhancing parent's resilience and belief that there is relation between the divine will and the origin of autism.

The current finding also stated that, mothers develop religion coping strategies like prayer and holy water. That is to say, they develop their coping strategies which aim to deal with their autistic children as well as to face their stressors in their long journey through faith and praying. Likewise, Tiffany (2010) and Gona *et al.*, (2016) also found out religious coping strategies serve to the parents as emotional aspects that concern the appeal to God, with the faith in supernatural powers' prayers and request for spiritual healing. Spirituality make parents to restore their patience, stress management and changing their view about their life.

In this study, social support occurred in various forms information concerning issues and emotional help. Five participants reported that spousal support considered as very useful in keeping them strong. It may come in different forms like advice, sharing responsibilities and having common agreement on issues relating to the child. Similarly, Bayat (2007) found working together, being flexible and communicating to be important characteristics in resilient families of children with autism. Consistently, the microsystem in the ecological model is helpful to understand the interaction that exists between immediate environments of an individual. The microsystem in ecological model presented that how families mobilize resources to ensure equilibrium.

Participants confirmed that they get support from their spouse, their immediate and extended family and support from autism centers. Likewise, other studies carried out in the US (Corre, Bonilla, & Reyes-MacPherson, 2011), Japan (Kimura & Yamazaki,

2013) Sweden (Bruce, Lilja, & Sundin, 2014) recognized that social support as coping strategies by many parents who are raising children with disabilities. Particularly, all mothers presented support which they get from the autism centers where, their children stay was prominent. The participants' reported that the centers enabled them to manage their own routine while their children stay in the centers. Similarly, Ecological theory presented that the interrelated nature of system within a person's environment.

Moreover, the autism centers arranged support group meeting which gave them opportunity to share their experiences. Participants reported that support group served them as a vital resource for mothers in their resilience journey. According to mothers, the support group provide platform where meet each other to interact and share ideas about their challenges and ways to support their children. The participants also demonstrated that support group helps them to know they are not the only ones in that particular situation. It also platform where zero stigmas are experienced as compared to the general community. Consistently, (Gray, 2006; Bayet, 2007; & Angela, 2013) demonstrated that support group allow mothers means of connecting with others who share same experiences. Similarly, the ecological theory supports this finding. At the Meso level, participants discussed various systems outside their immediate family that has been critical in their resilience process. Mothers identified autism center and support group as the two most important source of support in helping them remain strong. According to Bronfenbrenner's (1994) identified that the interrelated nature of system within a person's environment. Moreover, Support groups served as important resource for mothers in their resilience journey. The way these networks of families operate clearly shows how the Meso level in ecological model work where different microsystems

interact to achieve development. Mothers describing the support group as “family” that shows the level of safety and assurance that these group provide to them. For those who have small families or family support is limited the network serves as a replacement.

Ensuring the effective functioning of their journey, mothers in this study focus on the importance of learning about every dimension of raising a child with autism. Participant presented that this coping mechanism enable them to access any kind of information which help their children to develop basic life skills. Learning all you can, involved a range of activities for mothers from seeking out information and services for their children, to changing their home environment to enhance the safety and comfort for their child. The finding discovered that mothers tend to seek information from internet and books. Similarly, (Murphy and Tienery, 2007; Kirsten, 2008; Hossein *et al.*, 2013) stated that parents who raising a child with autism valued the information from different sources including internet and other parents of children with autism.

Moreover, learning all you can significantly influences the level of empowerment. This approach helped them to develop and maintain their sense of empowerment and problem-solving skills. Moreover, the participant reported that mothers consistently showed that they had learned so much from their child. They also found out conversation with other parents who shared the same experiences helped them how to navigate autism. (Heather *et al*, 2010) also demonstrated that parents in this study presented their own knowledge helps them to advocate on behalf of their children. Similarly, Strength perspective recognizes and values the resiliencies and resourcefulness of mothers of children with autism. Mothers' appear to harness and employ a vast array of strength in their maternal journey of raising children with autism (Saleeby, 2002).

Mothers reported that in sustaining their life, mothers expressed the importance of accepting their child with autism. This helped mothers to make positive life changes, experiencing personal benefits and learning something new about autism. Similarly, Lindsay (2014) and Roberta (2013) showed that acceptance to be extremely important as parents' life adjustment, to navigate system and parental empowerment.

Mothers also presented that accepting their life with child with autism paved the way to appreciate little achievement. They started to acknowledge each experience milestones in their autistic children. Despite the difference, mothers focused that these milestones were just as important as the "normal" milestones. Each milestone helped mothers to preserve sense of hope and feeling of strength in the face of adversity.

When parenting a child with disabilities, cherishing little progress and embracing each milestones is well documented within (Bayat, 2007; Glass, 2001 & Woodgate *et al.*, 2008). Parents in Bayat's study found that success no matter how big or small impacted their day in positive manner. Despite the ongoing challenges that faced families with child with autism; resilience became evident. (Both Glass and Woodgate *et al.*, 2008) explored that it was those small moments and milestones took parents to extreme pleasure. Likewise, cherishing little progress reflects how system within a person's environment affect each other as proposed by the ecological model (Bronfenbrenner, 1994). Thus, as mother's resilience affects a child development, so does the child little progress has a reciprocal impact on mothers' ability to remain strong over the period. The initial fears with the presence of a child with autism, revolves around how the child can develop and live an independent life. In this view, mothers spoke about how the child's little progress becomes a great motivation for them to keep moving on in life. For

mothers, seeing their children achieve certain milestones such as using toilet, eating independently and washing. These reduce mothers' stress and give them an assurance that these children can live their lives without being over dependent.

Mothers reported that navigating new journey let them to focus on the positive aspect of raising autistic children. Experiences of mothers extend beyond the nature of the relationship to shape mothers meaning making process. This provides a distinct orienting context for negotiating with their challenging journey. Participants demonstrated focusing on the positive aspect has shaped their worldview. They frequently described their autistic children facilitated new awareness about world which made them to focus on positive. This coping strategies helped mother to enhance their resilience, personal motivation and self-esteem. This represents coping strategies which emanate from within the individual that keep them going. Mothers' positive views seem to be adapted to make positive meaning and seeing strength out of challenges. Similarly, in the Luther et al. (2005) reframing is the most successful coping strategies that enable parents to define the problem in the positive way. Furthermore, (Bayat, 2007; Tunali &Power, 2002) stated that the importance of positive aspects of parenting a child with disabilities. This made parents to enhance sensitivity, confidence and assertiveness. All mothers reported that they possess inner strength, something unique to them which helped to manage the struggle of parenting child with autism. This shows that, all individual possesses some amount of strength regardless of their circumstance as explained by Saleeby (1996) in his strength perspective.

6. CHAPTER SIX: CONCLUSION AND IMPLICATION

6.1 Conclusion

This research provides a preliminary look at the stress and resilience of mothers that raise a child with autism. The incidence of autism had drastically impacted mothers' life. The lack of support and information during and after the diagnosis is more evident in this research. The role of mothers is so stretched due to different reasons; these are lack of prior information about autism and ways to manage behavioral problems of their children, inadequate services in hospitals and limited autism centers. These resulted mothers' sadness, despair and feeling of overwhelm. As result, mothers are more burdened with caring their autistic children. However, mothers also reported number of positive impacts of raising a child with autism. These life enhancements include redefining priorities in life, increased tolerance, patience and assertiveness.

The study also noted raising a child with autism appears to be a long stressful journey for many mothers, due to different reasons. These are the severity of their child behavior, uncertainty about their children future, financial difficulty and lack of self-care. Mothers exposed to stigma and discrimination attached to their children. As a result, mothers experienced the feeling of sadness, depression and confusion. Finally, despite the challenges and stress they encountered the study also indicated that mothers used various coping strategies that help them to strengthen their resilience. Mothers utilized various

support systems available in their social environment. These are mainly their spouses, family, support groups and autism centers. They also used religious coping like praying, , participating in church programs, taking their children to monasteries and holy water as significant coping method. In addition, mothers used their personal characteristics such as their knowledge, health and spirituality as means of coping. Moreover, the study demonstrated that the characteristics of their autistic children enhance mothers' resilience such as, showing progress and starting to do things by themselves that keep mothers to go in life. In general, this research serves to inform the existing literature in this area from around the world, but also provides greater insight into the need of mothers that raising autistic children in Ethiopia.

6.2 social work implications

Social work is a profession that stands for vulnerable group of the society. As this study revealed, mothers raising autistic children are one of the most vulnerable groups of people in Ethiopia. The study indicated those mothers encountered multi-dimensional challenges. As result, holistic intervention is necessary. Some of the interventions that needed to be addressed at different levels are presented below;

6.2.1 Intervention for the mothers

Psychosocial support is vital for mothers that living in stressful life situation. Mothers have experienced psychosocial challenges during and after the diagnosis. Thus, the social workers need to work with other professionals in hospital setting. This enables to provide appropriate counseling such as to provide psychological guidance about autism and ways to handle the behavioral problems of their children. Besides, providing training on life and stress management skills that help mothers to handle their life.

Furthermore, **strength perspective** is guiding principle of the social work profession. Moreover, **promoting the legal and human right issues** can also empower mothers to fight for their rights. As study found out that these mothers have strengths, capacities and potentials that enhance their resilience. Thus, social workers need to facilitate the resources that found in mothers and surrounding social environment to keep them going in their strength. In this way, mothers can strengthen their resilience against the stress. **Strengthen the existing support groups** is vital. Facilitate income generating activities for mothers' is other aspect of intervention that can provide the mothers with the means of tackling their financial burdens.

6.2.2. Intervention for the autistic children

Autistic children need to be included in the intervention process since they are a part of the struggle in mothers' journey. As result, in order to improve their well-being, social workers need to focus on the rights of these children in accessing education and services. Declaration of the Right of the Children included the right to education. As a result organizing inclusive schools and facilitating education and skill trainings will help to enhance the independence of autistic children.

6.2.3 Community level intervention

Most mothers are experiencing social stigma, discrimination and isolation which associated with their socio-cultural environment. The community's reaction to mothers and their autistic children that led mothers to live in stressful life situation. This indicated that changing the attitude and perception of the community is needed. Thus, organizing various awareness rising campaigning in collaboration with different stakeholders such as; public demonstration, media, forms, pamphlet, blogging on newspaper, social media

and community conversation platforms. These create an opportunity to mobilize community resources and supports.

6.2.4 Intervention for social services

As indicated in the study, mothers utilized support and resources from hospitals, autism centers and religious organization. As result, strengthening these services to enhance the level of support for mothers needs to be one area of the social work intervention. Facilitating psychosocial training for healthcare workers in the hospital that; enable them to have better understanding of autism and its intervention. Besides, organizing training for teachers and babysitters who works in autism center.

Furthermore, in Ethiopia there are only four autism centers nation-wide, two in Addis Ababa and one in Hawassa and Adama respectively. This is extremely low to as compared to the existing number of children in need of the service and the increasing number of new cases. Therefore, the government should take the leading role in facilitating the expansion of newly opening autism centers. There should also be a better linkage between institutions providing social services such as NGOs, GOs and private sector to jointly work together for better impact and also mobilizing resources to expand centers for autism.

Finally, religion and spirituality were found as a major coping mechanism by the participants of this study. Thus, it is important that there are support programs and/or self-help groups that give them a platform to express their ideas, to learn how to manage their emotions and sharing their experiences. Therefore, organizing partnership programs between religious institution, hospitals, schools and other related agencies for better support system for mothers' and their autistic children.

6.2.5 Implication to social work research

This study explores the experience of mothers in relation to their stress and resilience. However, the sample size is small that focus on small number of mothers from autism centers of two cities in Ethiopia. Therefore, a research design that employed a larger sample and/or multiple data collection; which would likely reveal a wider stress and resilience. Likewise, the inclusion of more diverse sample from would disclose interesting mothers' experiences that are embedded in various historical contexts.

This finding indicated some intervention strategies and support system that will make mothers life easier. Though, future research needs to be completed to access where else more intervention strategies and support systems can be put in place for mothers and their families. Besides, by further researching what mothers find the most stressful about having a child with autism. Thus, future healthcare professionals will have clear idea of where to support mothers and their autistic children, and what possible triggers will be in their work together. Further research on support system is vital to provide a clear understanding of where clients already feel supported and need more support. Furthermore, by researching the experiences of these "*New motherhood*" in depth, and uncovering stressors, needs, difficulties and resilience, future social workers will be in a better position to meet the needs of mothers who are raising a child with autism.

6.2.6 Implication for policy

Autistic children and their mothers are facing many challenges in hospital settings. Even though, mental health was mentioned in national health policy of country, the autistic children and their mothers' did not get enough support and treatment at healthcare settings. As result, the further development and endorsement of mental health

policy is necessary. This can ensure the responsibility and accountability of healthcare workers in hospital setting.

The education policy of Ethiopia and the millennium development goal promotes universal primary education for all children which automatically makes autistic children eligible for access to education. This can be achieved by expansion of autism centers and inclusive schools that integrated Applied Behavioral Therapy. Governmental organization like ministry of health, ministry of education and ministry of children youth and women need to work in collaboration for better policy development of autistic children. This can contribute to alleviating mothers' stress and provide bright future for children with autism.

Finally, one of the objectives of National Social Protection Policy of Ethiopia is to increase the coverage and access to health, education and other social welfare services. According to the policy paper, people with disabilities and people with mental health problems given due emphasis and special attention. This research gives insight about autistic children and their mothers' psychosocial problems to take action. Finally, it also provide enough information for the implementer of the policy who are led by Ministry of Labour and social affairs to articulate the problem and to facilitate suitable environment for the mothers' and their autistic children.

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Annex A

Informed Consent

My name is Rahel Fentahun .I am a post graduate student at Addis Ababa University, school of social work. Currently, I am doing a qualitative study on stress and resilience of mothers of children with autism. The study has a purpose to explore the stress and resilience of mothers of children with autism. This study will guarantee any direct benefit for estimated participant; though; the study will produce valuable information in relation with mothers who raising autistic children and autism. It will be road map for future researchers interested in this area. Equally, It will be a great input to major stakeholder like governmental organization, on-governmental organization, lawmakers and policy makers.

Your participation in the study will include in depth interview that with an estimated length of one hour and half. This interview will be audio recorded for later analysis. Besides I will assure confidentiality by not citing your actual name within the study report. Your participation is very valuable for the success of this study .I would politely request you to give clear answer to all questions .If you are not clear with the question, you may ask me to clarification .If you have any question and need further information about this study. You can contact me by calling on + 251-932-153181 or the student researcher advisor Dr.Fasil Nigusie on + 251-912-163174 and Addis Ababa University School of Social work on + 251-111-225950.If you understand the above

information, and if you are willing to participate in the study, please put your signature on the space provided below.

Participant Signature _____

Researcher Signature _____

I thank you very much for your cooperation!!

Appendix B

Personal Information:

Name (optional): _____

Sex: _____

Marital Status: _____

Educational Status: _____

Employment Status: _____

Question about your child with autism:

Name (optional): _____

Sex: _____

Age: _____

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

1.1 What was your and your family initial reaction when you were informed of your child's autism diagnosis; How old is he /she?

1.2 At what age did your child diagnosed with autism?

1.3 Where was the diagnosis carried out and who informed you about your child's case?

1.4 Have you got any psychological support from any professionals after the diagnosis?

1.5 Have you heard about autism before your child diagnosis? If the answer is yes, Can you tell me about what you knew about autism?

1.6 What do you think about the cause of autism in your child?

1.7 How do you define or perceive autism?

1.8 Do you believe that you have changed your parenting style after the diagnosis? How do you explain you're parenting style?

1.9 What are your daily routines relationships with your child?

1.10 What is the positive and negative impact of having a child with autism in your life and family?

1.11 How did extended families and community react to the diagnosis of autism?

1.12 How the community reacts to look like in public place with a child diagnosed with autism?

2. What are causes that bring stress in mothers of Children with autism?

2.1 What are the major negative psychological effects the family experienced due to the diagnosis of your child with autism (like depression, shock, guilt, self-blame, sleeplessnessetc.)?

2.2 What are the major factors that contribute to the family stress?

2.3 How having a child with autism affects your daily routine?

2.4 What are the major challenges you are facing in relation with the community?

2.5 What are the major economic challenges you faced after the diagnosis of a child with autism?

2.6 How do you explain raising a child in relation with its negative impact? (For example: -your relation with spouse, sibling or extended family)

2.7 How do you explain access to health support, special education and other services to your child? Are they accessible?

3. What are the coping strategies do mothers of children with autism develop to deal with their stress and to address the need of their autistic children?

3.1 How do you cope with challenges of caring an autistic child?

3.2 What are the major sources of support system that you accessed in relation to the stress faced by you?

3.3 Can you list down support services you accessed to cop up with your stress?

3.4 For how long have you waited to access the services and for how many years do your child accessed the services?

3.5 What is the contribution of support system that you accessed in improving your wellbeing as well as your autistic child?

3.7 Have you get encouragement, advice and information from friends and relatives?

3.8 Have you get any encouragement and support from persons in other families who have faced the same or similar problems?

3.9 How you get assistance from community agencies and programs designed to help families in your situation?

3.10 How do you explain your strength in relation with raising an autistic child?

Annex B

የመጠደቅ ስምምነት ቅጽ

ፊዩል ፊንታሁን ስባሳስቡ፡፡ በአዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ትምህርት ክፍል የድህረ ምረቃ ተማሪ ነኝ፡፡በአሁኑ ሰዓት የኮቪድ ችግር ያሰባቸው ሰዶችን የሚያሳድጉ ስናቶች የሚያጋጥማቸውን ችግሮች ስናመቃቋሚያ መንገዶች በተመለከተ ጥናት ስያካሂድኩ ነዉ፡፡የጥናቱ ዋና ስላማ የኮቪድ ችግር ያሰባቸው ሰዶች የሚያሳድጉ ስናቶች መስረት ያደረገ ነዉ፡፡ስለዚህም የጥናቱ ተሳታፊዎች በቀጥታ ተጠቃሚነት የሚያረጋግጥ ሲሆን በተሰደም የዚህ ችግር ስለባ የሆኑ ሰዶችን የሚያሳድጉ ስናቶች መረጃን በመስጠት የሚያገለግል ይሆናል፡፡እንዲሁም በዚህ ችግር ዙሪያ ጥናት ማድረግ ስሚፈልጉ ስሞኝዎች መንገድ ያሳያል፡፡ከዚህም በተጨማሪ ከባለ ድርሻ ስላላት ማስትሞ መንግስታዊ ስና መንግስታዊ ካልሆኑ ተቋማት ጋር ፤ሰህግ ስዉዉዎች ስና ፖሊሲ ስርቃቂዎች ስኩስ ድርሻ ያበርክታል፡፡

በዚህ ጥናት ላይ የሕገሰዎ ተሳትፎ ትስቅ ግብስት እንዳሰዉ ስማሳወቅ ስዉዳሰቡ፡፡ ይህን ቃለ መጠደቅ ስማካሂድ ስንድ ሰዓት ስስከ ስንድ ሰዓት ከሰላላ ደቂቃ የሚወስድ ነዉ፡፡ይህን ቃለ መጠደቅ ወደ ፊት ስሚደረገዉ የጥናቱ ትንተና ስዲያገለግል በመቅረዱ ድምጽ የሚቀዳ ይሆናል፡፡ በተጨማሪም ሚስጥራዊነቱ ስማስጠበቅ በመጠየቁ ዉስጥ የተገለጸዉ ሰም በጥናቱ ዉስጥ በቀጥታ ባለመጠቀም ሚስጥራዊነቱን ያረጋግጣል፡፡ስሚጠየቁት ጥያቄ ግልጽ ስና ትክክለኛዉን ምሳሽ እንዲሰጡበት በታላቅ ስክብሮት ስና ትህትና ስጠደቃሰቡ፡፡ስዉዳሰቡ፡፡ ሰጥናቱ መሳካት የሕገሰዎ ተሳትፎ ስጅግ ወሳኝ ነዉ፡፡ ስሚጠየቁት ጥያቄ ግልጽ ስና ትክክለኛዉን ምሳሽ እንዲሰጡ በታላቅ ስክብሮትና ትህትና ስጠደቃሰቡ፡፡ ጥያቄዉ ግልጽ ካልሆነሰዎ እንዲጠደቁኝ ስደፋፍሮታሰቡ፡፡ ጥናቱን በተመለከተ ማንኛዉም ጥያቄ ስና ተጨማሪ ማብራሪያ ካስፈለገዎ በዚህ ቁጥር ይደዉሱ + 251-932-153181 ወይም የስጢኒዉ ስማካሪ ዶር ፋሲል ንጉሴ + 251-912-163174 ስና አዲስ አበባ ዩኒቨርሲቲ የሶሻል ወርክ ትምህርት

ክፍል + 251-111-225950 :: ከሳይ ያለው መረጃ ግልጽ ከሆነውም እና በጥናቱ ተሳታፊ ስመሆን

ፈቃዳኛ ከሆኑ እባክዎ ከታች በተዘጋጀው ክፍት ቦታ ፊርማዎን ያስቀምጡ::

የተሳታፊ ፊርማ _____

የአጠኝነት ፊርማ _____

ስተሳተፊዎ አመሰግናለሁ!

ቅጥዎ ስ

የግል መረጃ:

ስም(ገድ ያደደስ): _____

ጾታ: _____

የጋብቻ ሁኔታ: _____

የትምህርት ደረጃ: _____

የስራ ሁኔታ: _____

የሶሪዝም ችግር ስላለበት ሰዎች የቀረበ ጥያቄ:

ስም(ገድ ያደደስ): _____

ጾታ: _____

እድሜ: _____

1. ሰዎች በሶሪዝም እንደተጠቀሱ በተነገረ ጊዜ የእርስዎ አስተያየት ና

ስምዎን ያሳውቁ?

1.1 ሰዎች በዚህ ችግር ተጠቂ መሆኑን በመጽመድ በተነገረው ጊዜ

የእርስዎ እና የቤተሰብዎ የመጽመድ ዓላማዎን ያውቁ?

1.2 ሰዎችን በመጽመድ በባለሙያ ያሳዩት በስንት ዓመቱ/ቷ ነው?

1.3 ምርመራው የት በምን ዓይነት ባለሙያ ነው የተካሄደው?

1.4 በምርመራዉ ውቅት የተሰጠዎት ምክር ወደም ድጋፍ ነበር? ካስ
ምን ዓይነት ምክርና ድጋፍ እንደሆነ ቢገልጹልን?

1.5 ከሰጅዎ ምርመራ በፊት ስለ ትረዝም ምንነት ያዉቁ ነበር?
ምስሰዎ ስዎን ከሆነ ስለችግሩ የሚያቁትን ሲነግሩኝ ይችላሉ?

1.6 በእርስዎ የግል አመለካከት የሰጅዎ ትረስት መሆን ምክንያት ምን
ይመስሉታል?

1.7 ትረዝምን እንዴት ይገልጹታል?

1.8 የሰጅዎን ከትረዝም ጋር መኖር ካዎቁ በኋላ የሰጅ እስተዳደግ
መንገዶች(ዘዴዎች) ተቀደረሱል ብለዉ ያስባሉ? ካተቀየረ በምን
ዓይነት መንገድ እንደሆነ ቢያብራሩልኝ?

1.9 በአጠቃላይ ከሰጅዎ ጋር ያለዉ የሰለት ክልለት ሕይወት ምን
እንደሚመስል ሲነግሩኝ ይችላሉ?

1.10 የሰጅዎ ትረስት መሆን በእርስዎና በቤተሰብዎ ላይ ያሳደረዉ
አዎንታዊ ወደም ስሎታዊ ተፅዕኖ ስለ?

1.11 ማሳበረሰቡ ወደም በአካባቢዎ ያሉ ሰዎች ስለሰጅዎ ትረስት
መሆን ምን ዓይነት አመለካከትና ምሳሽ ነበር የሰጡት? ምን ዓይነት
አመለካከትና እዉቀት አላቸዉ ብለዉ ያስባሉ?

1.12 በማሳበራዊ ቦታዎች ህብረተሰቡ በዚህ ችግር የተጠቁ ልጆችን
ሲያደ ያለዉ አመለካከት ምን ዓይነት ነዉ?

2. በትረዝም ችግር የተጠቁ ልጆችን የሚንከባከቡ እናቶች ጭንቀት
የሚያመጣዉ ምንድር ነዉ?

- 2.1 ከሕቴዝም ጋር የሚኖርን ልጅ በሚያሳድጉበት ወቅት የገጠመዎት ስነሰናዊ ችግር ነበር? ከነበረ ስለሆነታል፣ ቢያብራራህ፡፡ ስምሳሌ፡- (እንደ ድብርት፤ ድንጋጤ፤ የበደለኝነት ስሜት፤ እራስን መወደድ፤ እንቅስቃሴ ማጣት.....ወዘተ)?
- 2.2 ቤተሰብን ጭንቀት ወሰኑ የሚያስገቡ ሁኔታዎች ምንድን ናቸው?
- 2.3 ከሕቴዝም ጋር የሚኖርን ልጅ በማሳደግ በኩል ያገጠመዎት ማህበረሰባዊ ችግር ነበር?
- 2.4 ከልጅዎ ጋር ካሉት የስህተት ተስሰት ግንኙነት እና ህይወት ወሰኑ የሚያሳስቡት ወይም የሚያስጨንቁት ነገር ገጥሞት ያወቃል?
- 2.5 ልጅዎትን በመንከባከብ ምክንያት በስራዎ ሳይ ስራታዊ ተደራሽ ገጥሞት ያወቃሉ? ስምሳሌ፡- ከስራዎ ስለቀደሙ መወጣት፤ ስርዓቱ መታረስ ወይም መቀረት ሲገጥሙት ያወቃል?
- 2.6 ከልጅዎ ጋር በተያያዘ መስክ በቤተሰብዎ ሳይ የተሰየ ስራታዊ ተደራሽ ተፈጥሮ ያወቃል? ስምሳሌ፡- ከባለቤትዎ፤ ከልጆችዎ፤ ከቀርብ ዘመዶች ጋር ባለዎት ግንኙነት፡፡
- 2.7 ልጅዎን መቆጣጠር እና መንከባከብ በሰህተት ተሰሰት ህይወትዎ ሳይ ተደራሽ ስራዎ ያወቃል? ካስ ቢያብራራህ፡፡
- 2.8 ለልጅዎ ተጨማሪ ህክምና ትምህርትና እና ሲሎች ስገልግሉት ማግኘት ምን ያህል ቀሳሽ ወይም ከባድ እንደነበረ ቢገልጹህ፡፡
3. በሕቴዝም ችግር የተጠቃን ልጅ ከማሳደግ ጋር ያለውን ጭንቀት ከመቋቋም ስንዳር እናቶች የሚጠቀሙላቸው መቋቋም ዘዴዎች ምንድናቸው?

- 3.1 ኮቲከት የሆነን ልጅ ከማስታመም ጋር ያለውን ግድግዳ ሸክን ዲት ስያስፍት ነዉ?
- 3.2 ልጅዎን ከመርዳት ስንዳርጋቸው የስርዳታ ምንጭቱ ነዉ ያገለግሉት ቋማት ስነማን ናቸዉ?
- 3.3 ደህንነቱን ግርሰመቋቋም የስርዳታ ስገልግሉት ያገኙበትን ሲዘረዝሩ ሲነደቁ ሻሉ?
- 3.4 ስርዳታዉን ስማማችት ምን ያህል ጊዜ ጠቀሱ ምን ያህል ዓመታት ስገልግሉት ንገሰገኙ?
- 3.5 የተደረገ ስዎት ድጋፍ ስርዳታዎን ስልጅዎ ምን ስበረከት ?
- 3.7 ከዘመድ ከወዳጅ ስናከቤ ተሰብማ ደፍፈረዎ ፤ ምክርና የመረጃ ስገልግሉት ስኝተዉ ያዉቃሉ?
- 3.8 ተመሳሳይ ችግር ካጋጠማቸዉ ቤተሰቦች ድጋፍ ምክር ስኝተዉ ያዉቃሉ?
- 3.9 ከማህበረሰብ ወኪሎች ስናስገልግሉት ሰላማ ቋማት ስንደርሰዎባሰዓደነት ችግር ወሰኖላቸዉ ቤተሰብ ስርዳታ ተደርጎላቸዉ ያዉቃሉ?
- 3.10 በኮቲከት ዝምየተጠቃን ልጅ ከማሳደግ ጋር ተያደዞ ያሉትን ጥንካፌ ስንዲት ደገ ሰዱታሉ?