



**ADDIS ABABA UNIVERSITY
COLLEGE OF SOCIAL SCIENCES
SCHOOL OF SOCIAL WORK**

**The Challenges, Coping Mechanisms and Supports for Parents of
Children with Autism in Addis Ababa: The Case of Joy and
Nehemiah Autism Centers (A Mixed-Method Study)**

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Indiana University, USA, and Editor of Journal of Advances in Social Work)**

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Social Sciences at Addis Ababa University)**

**A Dissertation Submitted to School of Social Work in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy (PhD) in Social Work and
Social Development**

June, 2022

Addis Ababa, Ethiopia

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Abstract

Autism is a neuro-developmental disorder which causes impairments in multiple areas of development including social interaction, communication, and behavior. Parents face several challenges in raising a child with such developmental disabilities. In Ethiopia, around 600,000 individuals are living with autism. Developmental disorders such as autism are sometimes regarded as an evil-spirit or as a punishment from the supernatural/divine power in this country. The level of awareness, acceptance, and support for Autism Spectrum Disorder (ASD) in Ethiopia is very low. Joy and Nehemiah Autism Centers are the only two centers providing support for children with autism and their parents. The main objective of this study was to examine the challenges, coping mechanisms, and available support for parents of autistic children in Addis Ababa. To achieve this objective, a cross-sectional, exploratory sequential mixed method design was used. Respondents were 128 individuals from parents, professionals, and founders of the centers. Qualitative data were collected using in-depth and key informant interviews and were analyzed thematically. Six major themes were identified: (a) parents' awareness, perceptions, and reactions to the diagnosis of autism, (b) challenges of autism for parents, (c) coping mechanisms, (d) supports, (e) positive experiences of parents, and (f) advice for parents of a newly diagnosed child. Quantitative data were collected using a structured questionnaire to generate quantifiable data on (1) the levels of the challenges identified in the qualitative study (i.e., stress, stigma, and financial constraints), and (2) the relationships between these variables and the coping mechanisms used by the parents. Nearly all (n=97; 90%) of the parents reported financial constraints, followed by (n=84; 77.7%) stigma as measured by the Family Interview Schedule-Stigma Scale (FIS-SS), and (n=61; 56.5%) stress as measured by Parenting Stress Index-Short Form (PSI-SF). Structural Equation Modeling (SEM) indicated that stigma predicted parental stress (.40) and was mediated by coping mechanisms (-.67). Regarding the types of coping, parents were using spiritual support (M=14.036, SD=3.056), followed by reframing (M=27.000, SD=4.499), mobilizing family (M=14.841, SD=3.342), passive appraisal (M=17.390, SD=3.575), and the lowest through acquiring social support (M=32.146, SD=5.256) as measured by the Family Crisis Oriented Personal Evaluation Scales (F-COPES). Both informal and formal supports were identified and finally, conclusions, recommendations, and implications for social work practice are forwarded.

Keywords: Autism, Parents, Challenge, Coping Mechanisms, and Support

Declaration and Letter of Approval

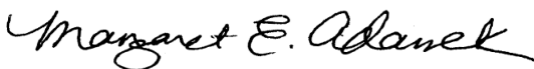
Declaration

I, Biruk Befkadu, Social Work and Social Development student hereby declared that this is my original work and to the best of my knowledge due acknowledgement has been made to materials used in this dissertation according to good scientific practice. This study has been presented in partial fulfillment of the requirement for a doctoral degree in Social Work and Social Development, which was not submitted for the award of degree in Addis Ababa University or any other university.

Letter of Approval

This is to certify that the dissertation entitled “*The Challenges, Coping Mechanisms and Supports for Parents of Children with Autism in Addis Ababa: The Case of Joy and Nehemiah Autism Centers (A Mixed-Method Study)*” is the original work of Biruk Befkadu Zawude, done under my close guidance and supervision. This study is submitted to graduate studies for examination with my approval as an advisor.

Name: Margaret E. Adamek (Professor, Director of PhD Program at Indiana University, and Editor of Journal of Advances in Social Work)

Signature: 

Date: February 26, 2022

Place: Addis Ababa, Ethiopia

Examining Board Members Approval Form

Addis Ababa University

School of Graduate Studies

This is to certify that the dissertation prepared by Biruk Befkadu Zawude entitled, “*The Challenges, Coping Mechanisms and Supports for Parents of Children with Autism in Addis Ababa: The Case of Joy and Nehemiah Autism Centers (A Mixed-Method Study)*” and submitted in the partial fulfillment of the requirements for the Degree of Doctoral Education in Social Work and Social Development complies with the regulations of the university and meets the accepted standards with respect to originality and quality.

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Acronyms

AMoS- Analysis of Moment Structure

APA- American Psychological Association

ASD- Autism Spectrum Disorder

CFI- Comparative Fit Index

CSA- Central Statistical Authority

DSM- Diagnostic and Statistical Manual for Mental Disorders

F-COPES- Family Crisis Oriented Personal Evaluation Scales

FIS-SS- Family Interview Schedule: Stigma Scale

FSS- Family Support Scale

GFI- Goodness of Fit Index

MMR- Mixed Method Research

MoH- Ministry of Health

NFI- Normed Fit Index

NGOs- Non-Governmental Organizations

NIMH- National Institute of Mental Health

PSI-SF- Parental Stress Index: Short Form

RMSEA- Root Mean Square Error of Approximation

RSMR- Root Mean Square Residual

SPSS- Statistical Package for Social Sciences

TLI- Tucker Lewis Index

WHO- World Health Organization

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CHAPTER ONE

1. Introduction

1.1. Background of the Study

Autism is a neuro-developmental disorder first introduced by American psychiatrist Leo Kanner in 1943. Autism affects a child's development in the core areas of communication, social interaction, and behavior (Notbohm, 2005). Kanner (1943) chose the word "autistic" because the children had a common "extreme aloneness from the beginning of life and obsessive desire for the preservation of sameness" (p. 217). Children with this disorder can be often extremely unresponsive to others, uncommunicative, repetitive, and rigid (Wing, Wing & Potter, 2002).

Impairment in social interaction, communication, restricted and repetitive patterns of behavior, interests, or activities are the main manifestations of a child affected by autism. Depending on the developmental stage of the child, additional manifestations such as hyperactivity, aggression, and delayed toilet training might also be used as further characteristics of the disorder (Neff & Faso, 2014). The American Psychiatric Association (2013) specified, "People with autism tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty in building friendships and they may be overly dependent on routines, highly sensitive to changes, or intensely focused on inappropriate items" (p. 12). These disorders are characterized by developmental deficits that impair normal personal, social, academic, and occupational functioning (American Psychiatric Association, 2013). Other behavioral, developmental, psychiatric, and medical problems co-occurring with autism can present the parent with difficult challenges to manage (Plumb, 2011).

A study conducted in the United States by Wing et al. (2002) claimed, a decade before their study, autism seemed to affect around one out of every 2,000 children in the US. However,

in recent years, there has been a steady increase in the number of children diagnosed with autism; and it now appears 1 in 68 children are believed to be identified with Autism Spectrum Disorder (ASD) in the United States, with boys affected four times more than girls (Centers for Disease Control and Prevention, 2014). This prevalence is substantially higher than that of a decade earlier. Similarly, prevalence rates of ASD are currently estimated to affect nearly 1 in 59 individuals in the United States, which represents a 120% increase in diagnoses since 2002 (Baio et al., 2018; Christensen et al., 2016). Autism spectrum disorder is growing faster than any other developmental disability (Twy, Connolly & Novak, 2007). Similar increases have been noted in the UK, Europe, and Japan (Landrigan, 2010, p. 219). Though the reason for the rapid increase is not known, autism affects children regardless of their color, race, and gender. Thus, the above figures and trends show that the prevalence of autism has increased at an alarming rate (Matson & Kozlowski, 2011).

In the African context, very few publications discuss the presence and clinical manifestations of autism; an official estimation of the prevalence of the problem in an African context is not available (Dixon, Badoe & Owusu, 2015). However, the prevalence of autism spectrum disorders among children with developmental disorders in Nigeria is noted to be 0.8% of the total population of children that attended clinics over one year (Bakare & Munir, 2011). In Ethiopia, there are no official data that indicate the prevalence of autism. According to the Nia Foundation (2010), the prevalence rate of autism in Ethiopia is roughly the same as for other regions of the world and in Ethiopia's population of more than 100 million, a fair estimation is that at least 530,000 children suffer from autism and related developmental disorders. Getnet (2013) presented an estimation of 0.7% of the total population as living with autism. The author stated, "Although it is difficult to know the number and the prevalence of autism in Ethiopia, it is

estimated that around 600,000 people are living with autism throughout the country” (p. 5).

Confirming this, Nia Foundation (2012) stated:

“Since Autism is found throughout the world and amongst all nations, nationalities and social classes, Ethiopia is not an exception. If one in every 100 children is diagnosed with autism in the U.S, we could fairly say that with Ethiopian's population of more than 100 million, we can estimate over 600,000 children are suffering from autism and related developmental disorders, with no access to rehabilitation, education, and training.” (p.3)

In Ethiopia and all over the world, the number of children affected by autism is increasing from time to time. Though clear data regarding the prevalence are not yet available in Ethiopia, a few private organizations are providing services to children affected by autism. There are two private organizations namely, Joy and Nehemiah Autism Center located in Addis Ababa. These organizations have been operational in Addis Ababa for the last few years providing various services to children with autism and their parents.

Parents face various challenges including economic, social, and psychological (Shibrei et al., 2003). Pennington (2002) argued that “because it removes individuals from society during the most productive years of their lives and limits their employment opportunities, the societal cost including long term medical treatment and custodial care lies on the parents” (p. 211). The economic problem is also associated with caregivers’ absenteeism from work, low productivity at workplaces, and quitting jobs (WHO, 2003). A study done in Butajira indicates that, of the problems that such families face, the economic problem is the primary one accounting for 71% of the respondents and women caregivers predominantly mothers who reported significantly more financial problems than men (Shibrei et al., 2003).

According to Schene, Wijngaarden and Koeter (1998), “Caring for a mentally ill [developmentally disordered] child is psychologically stressful for parents, they may confront

uncertainty, the emotion of shame, guilt, and anger” (p. 610). Similarly, Knudson and Coyle (2002) stated that “patient’s impairment of role functioning, self-care, inappropriate affect, social isolation and not responding well to medication are psychologically damaging for caregivers” (p. 170). The constant fear that the recurrence of illness may cause disruption is an additional stressor for the parents (MoH, 2007). Autism has a major impact on the lives of the affected children and their parents. The family of a child with autism often experiences disappointment, social isolation, added stress, frustration, and helplessness (Hailemichael, 2014). As a result, autism has been considered as one of the most complex and intractable developmental disorders with which parents may have to cope with.

There are two general ways of coping that families tend to use (Randall & Parker, 1999). Firstly, they make the child with autism the center of the family’s attention and effort and secondly, families may subjugate natural and spontaneous emotional expression, to show greater patience and understanding towards the child with autism. Thus, the parent’s ability to accept their child’s difficulty influences how a family functions. Supports focused on parents’ coping skills have reported positive results. Accordingly, Terry and Haynes (1998) suggested parent training in problem-solving and decision-making, communication skills, skills in accessing and utilizing social networks, and coping strategies such as positive self-statements, self-praise, and relaxation are considered important support services for parents.

Generally, autism is the fastest-growing developmental disorder (Matson & Kozlowski, 2011) and insufficient studies were conducted in the developing world (WHO, 2011). Intervention and educational institutions that give support to the parents of autistic children are very limited in Africa, particularly in Ethiopia. Therefore, this study aims to examine the challenges, coping mechanisms, and available supports for parents of children with autism.

1.2. Statement of the Problem

The global prevalence of autism spectrum disorder is one in 160 and it accounts for more than 7.6 million individuals (WHO, 2013). A rough estimation of individuals in Ethiopia that are affected by autism is 530,000 to 600,000 (Getnet, 2013; Nia Foundation, 2010). The awareness of autism in most Ethiopian communities is low to non-existent. Developmental disorders such as autism are generally attributed to an evil spirit. Due to such spiritual attributions, children with autism are tied up, locked in dark rooms, and deprived of their basic rights (Getnet, 2013).

The impact of autism is not only limited to the children, but it also affects parents in several ways. Although some parents send their children to school, most schools have no special arrangements for children with autism in Addis Ababa (Helen, 2016). However, children with autism, like all other children, must be allowed to grow and be cared for. Surely, they need no less food, no less socialization, and no less training than other children. “In a country like Ethiopia, where physical or mental impairments are considered as a curse or some sort of bad omen, opportunities to make life better or improve the situation of people with the problem is insignificant” (Letekidan, 2003, p. 6). As a result, “children with autism have been deprived of the opportunities to gain or improve their academic, social and communication skills” (J-CCARDD, 2005, p. 1). The lack of adequate awareness amongst the public, denial of the opportunities and the right to receive academic, social and communication skill training has interfered with their capacities and resourcefulness of their lives for the community.

Caring for a child with ASD comes with challenges and difficulties that affect the lives and mental health of the child’s parents (Seymour, 2013). Parents of autistic children tend to report lower quality of life, more depression, and greater pessimism about the future than parents of children without autism (Neff & Faso, 2014). Especially in less developed countries particularly in Africa, society’s lack of knowledge and awareness about autism has resulted in

social isolation, stigma, discrimination, and other consequences. For instance, in a Zambian study by Nyoni and Serpell (2012), several parents reported that the burden of responsibility for their child on the spectrum was worsened by unsympathetic comments by the general public which shows that many people are not aware of the condition and hence, stigmatizing to both the child and the parents. In a study in Uganda by Bwana and Kyohere (2001), caregivers of children with disabilities, who are mainly mothers or grandmothers, are subjected to stress and anxiety as a result of isolation from society. Similarly, as stated by Getnet (2013), more than 80% of autistic cases in Ethiopia face significant stigma. Moreover, these individuals are locked in dark rooms, including being chained to control their unusual behavior. Parents who became frustrated and tired of struggling to find help and support for their children established the few autism centers that exist in Ethiopia.

Studies have been conducted in other parts of the world. For example, Lyons, Leon, Roecker, and Dunleavy (2010) conducted a quantitative study in the United States to evaluate the effect of autism severity and parental coping techniques on stress in parents of children with ASD. The authors gathered data from 77 primary caregivers of children with ASD using questionnaires and analyzed the data using multiple regression analysis. The authors reported the severity of a child's autism symptoms and behavior plays a huge role in parental stress among families of children with autism.

Using a qualitative study, Mount and Dillon (2014) explored the experiences of parents of adolescents with ASD to understand the effect of the disorder on the lives of parents in the United Kingdom. Data were collected from nine parents of adolescents with ASD through individual semi-structured interviews and thematic analysis was used to analyze the data. The findings showed that parents indicated that the demands of raising a child with autism brought many challenges that affected the parents both mentally and physically. Some parents indicated

that their children's attendance in regular secondary school sometimes created challenges as the children came home with behavioral problems due to incidents at school. Despite that, parents reported that accepting their children's diagnoses improved their ability to support each other. Mount and Dillon (2014) suggested that better communication between families, schools, and other support services might help to improve the prognoses for individuals diagnosed with ASD and their families. Moreover, they also recommended further research be conducted on the lives of all individuals affected by ASD to raise society's awareness, understanding, acceptance, and empathy.

In Ethiopia, Meron (2006) conducted a study on autism and its impact on families. She collected data from 40 respondents by using a mixed method approach. The study revealed the impact of autism on the families as feelings of shame and hopelessness, and having difficulty participating in social activities. Her study showed that most parents do not have a clear idea about symptoms and how autism affects people. As a result, the families explained the condition as unrecognized mental illness and were confused (uncertain) about how to work effectively with autistic children. Efreem (2005) emphasized the role of parents in early intervention with autism. This study employed a qualitative approach and identified challenges faced by parents (such as lack of knowledge about autism, how to handle the situation of these children, and lack of regular schedule to communicate with professionals/therapists) in caring and early intervention with their autistic children. The study strongly recommended enhanced accessibility of information and knowledge for parents (to understand and select types of therapies) in early intervention with autism.

Unlike the above studies, our research question is mainly concerned with examining the challenges, coping mechanisms, and support systems to give an in-depth insight into the problem. Indeed, what has to be understood is that our research has a point of intersection with

some of these studies especially regarding the challenges of autism for the parent. However, the point of difference (especially with studies in the west), is in the context of the research, as the research was conducted in Ethiopia. Besides being developed in western culture, various theories are not as such subjected to verification whether they could enlighten the situation of autism in Ethiopia. For this reason, examining the problem in Ethiopia has paramount importance to fill the existing gaps in this regard.

Conducting research is important particularly in the field of autism as an emergent area of study and practice (Camarata, 2014; Zwaigenbaum et al., 2015). A clearer picture of the challenges along with the productive coping processes has essential implications for timely and effective support (Walsh, 2006). If this subject is left unstudied, it remains difficult to provide support for parents based on their needs and resiliencies to be built on. As indicated in the WHO's report on disability (2011), one of the main obstacles that hinder the establishment of efficient support programs for parents of children with autistic disorder in developing countries is the lack of studies that document the impact on parents of raising children with autism. Reflecting this view, Bello-Mojeeed, Bakare and Munir (2013) indicated little attention has been given to the pattern and impact on the primary caregivers (parents) of children with autism in sub-Saharan Africa. Similarly, Dykens (2015) stated, most of the publications focus on individuals with the disorder, and studies emphasizing parents raising a child with developmental disorders are still scarce. Therefore, to fill this gap, this study examined the challenges, coping mechanisms, and available supports for parents of children with autism in Addis Ababa. Awareness of the challenges and coping mechanisms that take into account the parents' distinctive ecological and developmental contexts will contribute to a more robust and systematic understanding of the resiliencies and support systems (Luthar, Sawyer, & Brown, 2006; Ungar, 2011; Walsh, 1996).

1.3. Objectives of the Study

1.3.1. General Objective

This research is aimed at describing the situation of parents of children living with autism in Addis Ababa. Accordingly, the general objective of the study is to assess the challenges, coping mechanisms, and available supports for parents raising children with autism in Addis Ababa, Ethiopia. This information was acquired through interview with parents who were receiving services from Joy and Nehemiah Autism Centers. In addition, supports provided by the centers for parents of children living with autism were also explored.

1.3.2. Specific Objectives

The specific objectives of the study were:

- To identify the challenges faced by parents of a child living with autism
- To determine the levels of stress, stigma, and financial challenges reported by the parents of children with autism
- To examine the coping mechanisms of parents living with autistic children
- To determine the most used coping mechanism by the parents
- To determine if the coping strategies mediates the relationship between stigma and stress among the parents of children with autism
- To explore the available support for parents of children at Joy and Nehemiah Autism Centers

1.4. Research Questions

Research questions are at the heart of the study and should reflect the line of inquiry (Yin, 2014). Perhaps the biggest challenge in defining the research questions is making sure that they sufficiently guide the research, while also not over-directing the study (Stake, 1995). Basing upon this ground, the study sought to answer the following research questions:

- 1) What are the challenges faced by parents of children with autism?
- 2) What levels of stress, stigma, and financial challenges do the parents of children with autism report?
- 3) What are the coping mechanisms of parents of autistic children?
- 4) Which of the identified coping mechanism do the parents mostly use?
- 5) Is the relationship between stigma and stress in parents of children with autism mediated by coping strategies?
- 6) What are the available supports for parents of children with autism diagnosed at Joy and Nehemiah Autism Centers?

1.5. Assumptions, Rationale and Justification for the Study

Family is the basic building block of any society. One way of creating a family is conventionally through marriage (the union of one man and a woman), which is essential for reproduction or providing one's offspring to promote collective survival as a society. The birth of a child is usually an eagerly expected phenomenon for the parents too. However, according to Aadil, Unjum, Afifa, and Zahoor (2014), having a child with autism or other developmental disabilities can perhaps modify and change most parents' quality and style of life to a significant degree. Nurturing a child with autism has a strong impact on the lives of the parents.

Autism has not received due attention in Ethiopia. This could easily be inferred from the lack of any policy or program by the government to address the issue. The efforts are very limited to two formally registered non-governmental organizations and ad hoc efforts of individuals. The two prominent actors in this regard are Joy Center, established by Nia Foundations, and Nehemiah Autism Centers which mainly operate in Addis Ababa. These organizations are endeavoring to improve the lives of children with autism and their families. Yet, the organizations are operating in a context (in the country) in which there is no framework

for autism care and treatment. In addition to the current global trend to pursue the use of empirically supported effective interventions and best practices, the lack of adequate studies in Ethiopia makes the practice challenging (Meressa, 2014; Tadesse, 2014; Tilahun, 2016). Therefore, there is limited research conducted in the area and there exists a huge research gap specifically in areas related to the perspective of parents who are striving to improve the functioning and integration of their children into the larger society.

Autism is generally regarded as a neuro-developmental disorder (Runswick-Cole, Timimi, & Mallett, 2016), or a serious developmental condition (Robins, Fein, Barton, & Green, 2001), and a disability that has a life-long effect on the children and their parents. Similarly, Lai, Goh, Oei, & Sung (2015) and Twoy et al. (2007) indicated that parenting a child with ASD is quite challenging.

Assumptions of the Study: Raising a child with autism has many challenges, which can significantly impact parental lives (Karst & Van Hecke, 2012). Behaviors some children with autism display can be stressful to the parents on a daily basis (Nealy, O'Hare, Powers, & Swick, 2012). Parents of children with ASD experience significantly more stress than parents of children without disabilities, and of parents whose children have other developmental disabilities (Samadi, McConkey, & Kelly, 2012). While there may be variations day-to-day, raising a child with ASD bring daily challenges and unknowns that can leave caregivers stressed and eager for providers to work with their child (Karst & Van Hecke, 2012). The common causes of stress and challenges range from a lack of support provided by formal agencies (Plant, 2011; Sanders & Morgan, 1997), to a lack of spousal support and a poor understanding of autism by the general public (Bitsika & Sharpley, 2004). Therefore, the parents need to develop coping strategies to increase their quality of life while raising their children (Lai et al., 2015).

While a proliferation of formal support groups for parents of children with ASD has been noted in the western world's research and literature, it varies in relation to content, method, and data on changes in parental wellbeing. Therefore, there is very little information regarding the challenges, coping mechanisms, supports, and parent-focused interventions that would be most capable of creating positive and better outcomes for parents in Africa in general and in Ethiopia in particular (Mandell & Salzer, 2007).

Knowledge Gaps: A review of the literature on the parents of children with ASD reveals that it is an under-researched area, with gaps in knowledge that warrants exploration. Our literature search led us to an array of texts on a variety of childhood disabilities and learning disorders, including autism. While such texts are written from a range of parent and professional perspectives, they are mostly child-centered (Kingston, 2007). This significant body of literature is extremely useful in delineating common characteristics, challenges, and solutions regarding the needs of children affected by various conditions. Likewise, there is a multitude of literature on an array of therapies, teaching methods, diets, and other topics related to improving the quality of children's lives (Kingston, 2007). However, we found a dearth of literature that considers the parental experience of raising a child with autism in Ethiopia with respect to the challenges, coping mechanisms, and supports, specifically using mixed and quantitative methodologies, and statistical findings are seldom analyzed in depth.

Methodological Gaps: There are many methodological constraints in the existing research on the parenting of children with ASD (Borntrager, Davis, Bernstein, & Gorman, 2009; Griffin & Gross, 2004); therefore, the present study aims to address some of these constraints to produce findings that have a greater level of dependability. The study is intended to advance knowledge in several areas:

- The use of multiple informants (parents, teachers, medical professionals, and founders of the centers) allows exploration of different perspectives, including an appreciation of the extent to which they converge. A multiple informant approach has been found to have better predictive strength in the general literature (Swearer, Siebecker, Johnson-Fredrichs, & Wang, 2010).
- Large and representative sample sizes permit the possibility of generalizing findings with a greater sense of confidence (Cohen, Manion, & Morrison, 2011).
- The use of mixed methods research (MMR) allows for greater depth and richness compared with purely quantitative or qualitative studies, in offering a detailed explanation of the findings (Johnson, Onwuegbuzie, & Turner, 2007). The use of multiple strategies within a single study to assess the challenges, coping mechanisms, and supports for parents of children with ASD enables comparisons to be made across the methods.

Practical Gaps (Gaps on Intervention): Parent training, counseling, financial, and material supports are extremely important for parents with children on the autism spectrum. However, limited research has been performed to uncover what parents perceive they need (services), or how well those needs are being met (Linares-Gonzalez, 2006; Siklos & Kerns, 2006). Research of support groups for parents of children with ASD has traditionally focused on helping parents to better manage their children's behavioural and autism-based difficulties. There is a paucity of research on the development of targeted interventions designed to train parents of children with ASD to manage the adverse psychosocial experiences they confront on a day-to-day basis. Clarification on the available supports for parents of a child with autism and what constitutes effective parent-focused support was also missing in the literature in Ethiopia. There

is thus a need for a study that delivers and evaluates, concerning parent mental health, the content and delivery format of the major services and parent support models from the literature.

A study by Murphy, Christian, Caplin, and Young (2006) showed that parents believe they receive inadequate counseling, emotional support, and specific diagnostic support. Bromley, Hare, Davison, and Emerson (2004) found,

At present, it is possible that such interventions are not being adequately provided, as the psychological wellbeing of parents does not necessarily come within the remit of services for children with developmental disabilities. This is a potentially important area of development for such service. (p. 421)

Parents need to have access to emotionally and cognitively supportive resources (Linares-Gonzalez, 2006). Thus, a study that considers what services are being offered for parents and what services parents feel are necessary to help them cope is crucial.

Generally, little is known about autism in Africa: the vast majority of autism research studies to date have been conducted in Western, high-income countries (Durkin et al. 2015), resulting in a research gap concerning studies from low-income countries like Ethiopia. Due to a lack of epidemiological studies, the prevalence of autism in Africa is unknown (Elsabbagh et al. 2012). The few autism studies conducted in Africa indicate a lack of knowledge and awareness about autism, inadequate mental healthcare facilities, and a severe shortage of trained personnel (Bakare & Munir, 2011). No African country has published policies or good practice guidelines for an ASD assessment, treatment, education and support (De Vries, 2016). A report of an autism meeting attended by 47 delegates from 14 African countries highlighted the lack of available autism services throughout Africa and the need to raise awareness and develop autism screening, training, and service strategies on the continent (Ruparelia et al., 2016).

Similar to other African countries, Ethiopia has limited autism service provision. The detection of and care for children with autism in Ethiopia is further impeded by the stigma surrounding mental health (Shibre et al., 2003) and misconceptions about the causes of developmental disability and mental illness (Alem, Jacobsson, Araya, Kebede, & Kullgren, 1999). These findings illustrate the great challenges experienced by parents of children with developmental disorders in Ethiopia. By and large, as a contribution to the literature, the significance of this study was the possibility to contribute to knowledge on parenting a child with autism. It has also implications for positive social change by increasing awareness and understanding of parents in Addis Ababa concerning the challenges, coping mechanisms, and supports for parents of children with autism.

1.6. Scope of the Study

In Ethiopia, institutions for autism are very limited; only two centers (Joy and Nehemiah) exclusively provide services for children living with autism and their parents. Both centers are located in the capital city of Ethiopia, Addis Ababa. The current study examined the challenges, coping mechanisms, and supports for parents of autistic children at Joy and Nehemiah Centers of Autism. The study was delimited to parents of children with autism who regularly came to the centers for support. Parents who were not actively participating in the education of their children would be difficult to find and were not included in this inquiry. Therefore, geographically, this study is delimited to the capital of Ethiopia, Addis Ababa and conceptually, the scope of the study is delineated to the challenges, coping mechanisms, and available support for parents of children living with autism.

1.7. Significance of the Study

There is a paucity of literature on autism in developing countries (WHO, 2013) including Ethiopia. Considering the shortage of studies that target mental health issues (developmental disorders) in general and the long-term care and treatment experience of families or parents in particular (WHO & MoH, 2006), we believe this study would provide insight into the challenges, coping mechanisms, and supports for parents of children living with autism in Addis Ababa.

Studying the challenges, coping mechanisms, and available support for parents living with autistic children in Ethiopia would contribute to promoting the well-being of challenged parents and their children. There is a lack of available care and support services for children with autism and their parents. There are only two centers to address the needs of parents of a child with autism and their children. The study would provide extensive and detailed information on the connotation of what it means to be a parent of a child with autism. This study is also important to providing relevant and updated information on the issue to parents, professionals, and centers that work with autistic children and the community at large. In addition, understanding the challenging situation of these parents can inform the designing of suitable care and support services at a national level.

The findings may also provide information for policymakers as well as school owners to think about the extra support needed for these parents. On the other hand, this study can inform policymakers and other interested groups as they consider autism on the national agenda, design policies, develop implementation strategies, and ensure a better life for the parents as well as the children living with autism. It also serves as a benchmark for governmental and non-governmental organizations like policymakers, donors, program developers, and international organizations to facilitate opportunities for parents regarding awareness-raising, counseling, and pecuniary assistance in the treatment of their children. Finally, this study may serve as a

springboard for researchers, academicians, practitioners, and other stakeholders interested in the area.

1.8. Operational Definitions of Terms

- **Autism:** The term ‘autism’ is used as an umbrella term to refer to all autism spectrum disorders. Autism is a pervasive developmental disorder characterized by the physical, cognitive, emotional, and spiritual impairment of the child (National Institute of Mental Health/NIMH, 2011). Simply put, it is a developmental disability associated with impairment in social skills and communication.
- **Autism Spectrum Disorder (ASD):** A group of neurodevelopmental disorders including autistic disorder, Asperger’s disorder, pervasive developmental disorder not otherwise specified, Rett’s disorder, and childhood disintegrative disorder (NIMH, 2011). The disorders are marked by symptoms of repetitive behavior and impairments in communication and social skills (NIMH, 2011).
- **Mental Illness:** also called a mental disorder or psychiatric disorder, is defined as a mental, behavioral, or emotional disorder that impairs a person’s ability to function effectively (in a work setting, school, and social relationships). It can also be viewed as a disability or disturbance in the functioning of the individual. The most common mental illnesses are classified as anxiety disorders, mood disorders, schizophrenia, dementia, and addictive disorders, though there are a wide variety of other important disorders such as personality disorders and eating disorders (American Psychiatric Association, 2013).
- **Parents:** A caretaker of a child that can be the biological/birth mother, father or legal guardian of the autistic child, who is living and raising the child with autism and provides care and support for that child.

- **Parenting:** The concept of parenting focuses on teaching/guiding, supervising, and disciplining a family by the adult(s) in charge of the unit (Turnbull & Turnbull, 2004).
- **Family:** Individuals or relatives living with or caring for a child with autism.
- **Challenge:** Any difficulty faced by parents in living with or caring for a child diagnosed with autism. In other words, it refers to situations that are difficult for parents of children with autism in living with or raising their children.
- **Psychological Challenges:** Difficulties people encounter that cause them unpleasant feelings such as unhappiness, fear, worry, anxiety, stress, and hopelessness that can affect their activities in day-to-day living and social functioning.
- **Social Challenges:** Stigma, stereotypes, and discrimination experienced by parents by virtue of having a child with autism. It also refers to difficulties that people encounter while interacting with people in the community or engaging in social activities.
- **Economic Challenges:** Financial burden (like medical costs for treatment) experienced by parents in caring for a child diagnosed with autism.
- **Coping Mechanisms:** Strategies (mechanisms that include thoughts, feelings, and actions) of adjustment/adaptation to environmental stresses and challenges, to enhance control over behavior. Therefore, it refers to efforts (adaptation mechanisms) made by parents to address the challenges faced because of having a child living with autism.
- **Coping:** As defined by Lazarus and Folkman (1991, cited in Weldeab, 2006): "... coping is a dynamic process which is changing thoughts and acts that the individual uses to manage the external and/or internal demands of a specific stressor–environment transaction that is appraised as stressful" (p. 59). Therefore, it is how a parent deals with the challenges of autism.
- **Support:** The material, financial, and psychosocial services (like counseling and training) that parents of children are provided to cope with the challenge of raising an autistic child. Such support includes both material and non-material provisions for the

parents. It is also help/assistance from family, relatives, friends, and professionals in difficult, stressful times when parenting a child with autism (Taylor, 2011).

- **Support Services:** Formal services to help and improve the life and welfare of children with autism and their parents such as special educational, daycare, and therapy services (Maciver et al., 2010).
- **Intervention:** A program or strategy designed to produce a change in behavior or to improve the situation of autistic children and/or parents.

1.9. Organization of the Study

This report of the study is organized and presented in seven chapters. The first chapter, chapter one, is an introductory chapter that sets the overall background for the study and provides a statement of the problem, objectives of the study, research questions, assumptions, and justification for the study, scope of the study, the significance of the study, and operational definitions of terms. Chapter Two is a literature review and contains the history and definition of autism, causes of autism, and parents' perception of causes of autism across culture, types, and symptoms of autism, diagnosis, treatment options, magnitude and trends of the problem, challenges of autism for parents, coping mechanisms of parents, and available support for parents of a child living with autism, as well as theoretical and conceptual frameworks of the study. The overall methods including the philosophy of the study are discussed in Chapter Three, which describes the research method, research design, study area, sources of data, unit of analysis, population and sample size, sampling technique, eligibility criteria, variables of the study, methods of data collection and data collection procedure, plan of data analysis, data quality assurance, and ethical considerations. In chapters Four and Five, the results, analysis, and findings of the qualitative and quantitative data are presented. Chapter Six provides a discussion of the major findings in relation to the reviewed literature. Finally, Chapter Seven presents conclusions, recommendations, and implications for social work and social development in terms of policy, education, services, and research.

CHAPTER TWO

2. Literature Review

“Variations in developmental processes and outcomes are considered a joint function of the environment and of a developing person” Bronfenbrenner (1992, p. 197).

2.1. History and Definition of Autism

The word autism is coined from the Greek word ‘autos’ meaning ‘self.’ Leo Kanner, a child psychiatrist at John Hopkins University, first used the term in 1943 (Ozonoff, Dawson, & Mcpartland, 2002, p. 5). According to Kanner’s earliest diagnoses of eleven children with autism, the children displayed ‘resistance to change.’ He used the term “resistance to change- to refer to some of the unusual behaviors frequently seen in autistic children like stereotyped, purposeless motor behaviors such as body rocking, hand flapping, toe walking, and unusual staring” (Volkmar & Wiesner, 2009, p. 26). All eleven children were unable to develop normal relationships with people or displayed ‘extreme autistic aloofness’ (Kanner, 1943). In behavioral categories, they were different from the general child clinical population. With normal physical appearance, the children showed delay in speech development, engaging in repetitive and stereotyped play activity... in very early infancy (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2007).

Autism is a complex neurodevelopmental disorder that is characterized by impairment in social interaction, communication and inappropriate behavior, interest, and/or activity (WHO, 2013). Thus, it is a severe developmental disability marked by impairment of communication, and social and emotional functioning (Volkmar & Wiesner, 2009). It is also a lifelong disorder that occurs in all racial, ethnic, and social groups (Volk, Lurmann, Hertz-Picciotto, McConnell & Campbell, 2014).

Autism is described as a spectrum disorder that manifests itself across a wide range of behaviors from mild to severe. The symptoms of autism involve three major areas of development: social, communication, and behavior (Weiss & Lunskey, 2011). Specifically, a person with autism may have difficulty in reciprocal social interactions with others; exhibit self-injurious or repetitive behaviors; and not communicate with others in developmentally appropriate ways. According to a report of the American National Research Council (2001), most autistic children often have problems in communication, avoid eye contact, and show limited attachment to others. A child with autism appears to live in his/her own world, showing little interest in others, and focuses on a consistent routine that includes an interest in repeating odd and peculiar behaviors.

2.2. Causes of Autism

Autism is a multifactorial disorder caused by many factors including complex genetic interactions, nutritional deficiencies, pre and post-natal exposure to chemicals or viruses, and dysfunctional immune systems (Norris, 2006). According to Volkmar and Wiesner (2009), most scientists agree that genes are one of the risk factors that can make a person more likely to develop an ASD. For example, two identical twins are more likely to have autism than two fraternal twins (EHCPCD/European Commission Health and Consumer Protection Directorate, 2005). Folstein and Rutter (1978) carried out the first study that looked at the correlation between twins and ASD. In a study that included 21 pairs of twin boys, 11 identical and 10 fraternal, the authors found concordance for autism in four of the 11 identical sets of twins and none in the fraternal twins (Folstein & Rutter, 1978). Supporting this, Norris (2006) concluded, in her study on families in which more than one member is affected with ASD, that the identical twin of an individual with ASD has more than a 90% chance of being affected. A fraternal twin

or sibling of an affected individual has a 15% chance of having ASD, and a parent of a child with ASD has a 10% chance of having a child with ASD.

Several environmental agents were identified as strong contributors to developmental disabilities in human beings. As indicated by Landrigan (2010), studies on lead, methyl, and mercury have documented that toxic chemicals can damage the developing human brain to produce a spectrum of neurodevelopmental disorders. The author further argued that children today are at risk of exposure to synthetic chemicals, termed High Production Volume (HPV chemicals), which are found in consumer goods, cosmetics, medications, motor fuels, and building materials.

While the exact cause of autism is not yet known, “researchers suggest gene and environmental factors as an important element” (NIMH, 2011, p. 2). Scientists who study genetic factors as a cause of autism focus on identifying the specific genes involved. The environmental aspect as a cause of autism is about environmental attributes from outside of the body that can affect one’s health. Siegel (2003) presented (1) the growth of a physically different brain with the innate process of genetic differences and (2) the write-up of experience on a physically different brain is stated as a cause of autism. In addition to the above-mentioned causes, there are risk factors associated with autism: parental age, fertility treatments, pregnancy risks, and risks to fetal development (Siegel, 1996). Apart from this, chronic problems related to reproductive health, the prevalence of diseases like malaria, poverty (inability to meet basic needs), and food insecurity are assumed to contribute to the increased prevalence of ASD and pervasive developmental disorder (PDD) in [Ethiopia and] other low-income countries (Torres et al., 2003).

2.2.1. Parents' Perception of the Causes of Autism across Culture

According to the literature reviewed, parents' view of the causes of their children's neurological disability varies from one culture to the other. For instance, as indicated in a study by Russell and Norwich (2012) in the United Kingdom, parents' perception of the causes of their child's ASD symptoms included biological factors and neurological differences. In the United States, Altieri (2006) found that a majority of parents agreed with scientific findings that no one has discovered an exact cause of autism; however, Measles, Mumps, and Rubella (MMR) vaccination, and genetic and/or environmental causes were the most frequently listed causes.

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

In a Jamaican study by Mann (2013), most mothers believed that they were fated by God to have an autistic child and some thought there was a genetic risk that led to their child's symptoms. As the primary caregivers, mothers in South Korea attributed the cause of their child's autism to the mother's prenatal mood and the post-natal diet (Grinker et al., 2012).

In most African studies (Anthony, 2009; Bakare et al., 2009; Nyoni & Serpell, 2012) ASD is often viewed as a result of some misfortune or wrongdoing by the parents or the ancestors of the autistic child including witchcraft and evil spirits (Bello-Mojeeed et al., 2013). For instance, as demonstrated in Bakare et al. (2009), participants from Nigeria often blame/attribute ASD on witchcraft spirits, hereditary causes or just simply bad parenting and

view mothers as cold and uncomfortable with their children. Correspondingly, a dissertation by Anthony (2009) provided a look at the understanding of autism in Ghana. Parents, especially mothers, were the ones to be blamed for their child's symptoms due to either not providing quality prenatal care, a failed abortion attempt involving ingestion of toxins, or due to experiencing some illness/accident during the course of their pregnancy as the cause for ASD.

On the other hand, according to Nyoni and Serpell's (2012) phenomenological study in Zambia, several families reported that the cause of ASD was witchcraft and/or non-compliance with customs and traditional norms in marriage. Nyoni and Serpell further stated that such thoughts lead to family conflicts on gender roles, marital conflicts, poor parental care, and denial of the child's condition by parents, particularly by the father, mainly if the child with ASD is a first-born son, who traditionally is treasured.

Generally, the reviewed articles and studies on the causes of autism present various genetic/biological and environmental causes. Common explanations for autism include complex genetic interactions, nutritional deficiencies, pre and post-natal exposure to chemicals, viruses, and/or teratogens are found to be common explanations for autism. However, parents' explanation about the cause of their children's developmental disability differs across studies in different countries and cultures. Most of the parents from well-developed countries raise more logical explanations, whereas parents from less developed and developing countries specifically from Africa raise more cultural explanations.

2.3. Types and Symptoms of Autism Spectrum Disorder

2.3.1. Types of ASD

Autism spectrum disorder is a lifelong disorder, usually diagnosed after three years of age and persisting through adulthood, with no identified etiology and/or healing. The deficits displayed by individuals having ASD affect the most vital aspects of quality of life, including interacting with other people, communicating ideas and feelings, and understanding what others feel or think (American National Research Council, 2001).

Because of the complexity of the disorder, three sets of criteria are officially used within the clinical professions to confirm the presence of an ASD, one being the DSM-IV-TR/Diagnostic and Statistical Manual, 4th edition, Text Revision (American Psychiatric Association, 2000), another, the lately released DSM-V/5th edition (American Psychiatric Association, 2013), and the other is the World Health Organization's (2004) International Classification of Diseases, 10th version (ICD-10). Within psychological and social work practice and interventions, the DSM criterion is utilized most frequently (Fitzgerald & Myers, 2014).

Within the DSM-IV-TR (American Psychiatric Association, 2000) autism is defined and classified as:

“...severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities. The qualitative impairments that define these conditions are distinctly deviant relative to the individual's developmental level or mental age... [this category includes] Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified” (p. 69).

Autism spectrum disorder is divided into five diagnostic subcategories. According to the DSM-IV-TR (American Psychiatric Association, 2000):

*“**Autistic disorder** is diagnosed if an individual displays difficulties with six or more symptoms across the three areas of communication, social interaction, and repetitive/stereotyped behaviours or interests, and must present before three years of age. **Asperger’s disorder** is similar to autistic disorder, however, a person diagnosed with Asperger’s usually displays normal communication development as well as “typical” levels of cognitive and self-help skill development. **Rett’s disorder** is referred to as the most physically disabling of the ASDs, is much rarer than autistic and Asperger’s disorders, and is most often seen in females as a regression in social, language, and motor skills. Similar to autistic disorder, **childhood disintegrative disorder** presents as difficulties with communication, social interaction, and repetitive/stereotyped behaviours. However, differentiating this disorder is the later onset (up to ten years of age) and normal developments until disintegrative losses begin. Lastly, the fifth diagnosis, **Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)** is used when impairments similar to the above diagnoses are present, but not all criteria are met”* (cited in Weastell, 2017, p. 2).

DSM-IV identified five disorders under the broader category of Pervasive developmental disorder based on the psychopathology of autism spectrum disorder. The American Psychiatric Association (2013, p. 809), under its DSM-V, has made the following changes and elaborated the categories of autism spectrum disorder as:

- A. Autistic Disorder:** To qualify for a diagnosis of autistic disorder, DSM-IV-TR is fully taken into consideration. Such impairment on social interactions (lack of social

reciprocity), impairment in eye contact, failure to develop peer relationships, impairment in communication (delay in language acquisition, inability to initiate or sustain a conversation, repetitive use of language), and stereotypic pattern of behavior (restricted pattern of interest, inflexible routines, and repetitive motor mannerisms), all with onset before three years of age.

- B. *Asperger's Disorder:*** Asperger's disorder is a part of autism spectrum disorder in which impairment in social interactions and stereotypic patterns of behavior are present with normal intelligence and relatively normal language development. Individuals with Asperger's disorder do not have any clinically significant delays in language or cognitive development.
- C. *Childhood Disintegrative Disorder (CDD):*** CDD, also called Heller's syndrome, is a relatively rare disorder that presents with features of normal development until two years of age and then loss of social, intellectual, and language skills by 3–4 years of age (by 10 years of age as per DSM-IV-TR).
- D. *Rett's Disorder:*** Rett's disorder presents with normal development until at least 6 months of age followed by a deceleration in head growth, loss of social skills, mental retardation, and characteristic handwringing movements. DSM-V is proposing to exclude this disorder from the DSM system, as autistic symptoms are present for only a minimal period and it is categorized under genetically identifiable neurological disorder.
- E. *Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS):*** DSM-IV-TR reserves this category for individuals who present with impairment in social interactions, communication skills, or stereotypic behaviors but do not meet the full diagnostic criteria

of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and Rett's disorder.

Generally, PDD-NOS have been removed based on a reported lack of research evidence supporting this distinction (Broadstock, 2014). In the DSM-V, though it is not explicitly written, there is an intention to propose three subcategories of ASD: autistic disorder, Asperger's disorder, and childhood disintegrative disorder. Skeptically, rather than specifying the subcategories into three or five, the DSM-5 has introduced severity indicators and descriptive "specifiers" to describe the types of supports an individual may require. Also, there is now a reference/preference of autism spectrum disorder over pervasive developmental disorder. As Rett's disorder is genetically identifiable as a neurological disorder, this is also no longer included in the ASD category (Broadstock, 2014). Less significant changes have also been made, such as changes to the rigid requirement of symptom presence before age three, symptom domain re-arrangement, the inclusion of unusual sensory sensitivities, and changes to a minimum number of diagnostic criteria. The changes to the DSM-5 category and subcategories are more attuned to the common practice within public health services (Weastell, 2017).

While the DSM-5 is more in line with current thinking about ASD spectrum, consensus had not been reached among professionals in the field on the use of the DSM-5 within public health services (Weastell, 2017). Generally, Pathappillil (2011) stated, ASD changes the way nerve cells and synapses connect and organize information and thus affects the normal processing in the brain. In line with this statement, Bashir, Bashir, Lone, and Ahmed (2014) suggested long-term impairments within the domains of social interaction, communication, play, imagination, and a restricted range of behavior as symptoms or characteristics of ASD.

2.3.2. Symptoms of Autism

In 1943, Dr. Leo Kanner, who worked at John Hopkins hospital, studied a group of 11 children and introduced the title of early infantile autism to the English language (Langan, 2011, cited in Seepersad, 2016, p. 21). Similarly, Dr. Hans Asperger, a German scientist, discovered a milder form of the disorder which was known as Asperger's syndrome (Bauman, 2010). Today, autism, Asperger's disorder, and childhood disintegrative disorder, are defined and recorded in the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association as Autism Spectrum Disorders (ASD) (American Psychiatric Association, 2013). These disorders are classified by various degrees of impairment in communication skills, social interactions, and by limited, repetitive, and stereotyped patterns of behavior.

Autism symptoms typically can be identified in children as young as 18 months, and the American Academy of Pediatrics recommends developmental screening of all children by age 24 months. Nevertheless, "many children with autism especially those with only mild or limited speech delays may not be diagnosed until they are of school-age when parents become concerned about an inability to make friends and teachers notice difficulties with peer interactions" (Blumberg et al., 2013, p. 2). Similarly, Dawson, Mottron, and Gernsbacher (2008) claimed that as the symptoms of autism vary, two children with autism may display strikingly different skills. For instance, some children may exhibit signs of autism in early infancy, while others who develop normally for the first six months or years of life and may unexpectedly become inhibited or in some cases lost language skills.

Therefore, symptoms of autism vary from one child to the other but in general, they fall into social impairment, communication difficulties, and repetitive and stereotyped behaviors (National Institute of Mental Health [NIMH], 2011). The American Psychiatric Association

(1994) also specified three criteria that are used to diagnose autism. These criteria are composed of the main distinctive characteristics of autism:

- Social interaction- severe abnormality of reciprocal social relatedness,
- Communication- severe abnormality of communication development, and
- Behavior- restricted, repetitive behavior, and interest. Correspondingly, the American

Psychiatric Association (2013) asserted there are usually three major developmental areas that are affected by autism: impaired social development, language, and behavior.

2.3.2.1. Impaired Social Development

Impaired social interaction is one of the main features of autism. Children with autism have difficulties interacting both with peers and adults. From infancy to age three they exhibit a lack of social skills such as disinterest in social games, having little attention to family members, having abnormal eye contact or limited attention to other people, and poor playing skills. Children with autism demonstrate rigidity and limitations in social interaction and have problems in establishing relationships. This is because they are unable to process social information properly and to use appropriate social skills to create and maintain relationships (Columbia Ministry of Education, 2000).

Tuchman (2003) explains that social impairment experienced by individuals with autism includes being socially isolated and exhibiting inappropriate social behavior (as cited in Keenan et al., 2007, p. 28). The participation of children diagnosed with autism in social activities, on their initiation is very limited. Parents reported that children diagnosed with autism exhibit symptoms of impaired social development. These symptoms as presented by most parents are “isolation from the surrounding environment, failure to play like other children, loss of

attraction/attention, empty gaze, and apparent deafness/hearing impairment” (Gillberg et al., 1990 as cited in Keenan et al., 2007, p. 29).

Since they have difficulties in language processing and communication, they are unable to understand social situations and the environment in general. This in turn makes children with autism disinterested in the world of people around them, and they typically do not interact with others as most people do. According to the American Psychiatric Association (1994), although the type and degree of social skill severity differ from person to person, an autistic child, in general, lacks imaginative or social play and/or shows limited pleasure in social games.

Some children tend to have poor eye contact and appear not to hear at times. Other children were unable to be empathic, that is, they tended to be unaware of others’ emotions and to understand the emotions of others (Elliot, 2013). Additionally, since they have trouble understanding people’s feelings, they have difficulties making friends and show significant difficulty with any interaction that requires knowledge of other people and what they think or know. As a result, autistic children have an impaired ability to initiate or sustain a conversation. Some children with autism show difficulty noticing people who are talking to them whereas others might be interested in people but do not know how to talk, play, or relate to them (Ruble & Gallagher, 2004). They tend to be withdrawn as they prefer to retreat to their world and play by themselves (Biever, 2012).

Orsmond, Krauss, and Seltzer (2004) investigated friendships amongst individuals with ASD and reported that many individuals with ASD had difficulties developing friendships. Few of them considered themselves to have even one true friend, and even those who did often still reported feeling lonely. Even though many adults with ASD do report that they have friends,

their relationships are often depicted as containing lower levels of companionship, closeness, security, and intimacy, and to be less enjoyable than those of adults without ASD (Bauminger, Solomon, & Rogers, 2010). This study demonstrated that in comparison with typically developing individuals, those with ASD are less likely to develop and maintain long-lasting, reciprocated, and stable friendships. Similarly, in a study by Orsmond et al. (2004), it was often reported that very few of the individuals with autism appear to develop and maintain quality friendships into adulthood.

Generally, social impairments typically affect how individuals with ASD understand and react to the world surrounding them (Wing & Gould, 1979). These social deficits are considered to impact adult outcomes and contribute to outcomes that have been repeatedly shown among adults with ASD, such as unemployment and underemployment, paucity of friendships and romantic relationships, and low rates of independent living (Farley et al., 2009).

2.3.2.2. Impaired Language and Communication

Language is usually impaired among children diagnosed with autism. Jordan and Powell (1995) state that in many children with autism, abnormalities and delays in the development of language are obvious, having symptom of communication difficulties (cited in Keenan et al., 2007, p. 29). The authors claimed that about 40% of children with autism do not talk at all and others have echolalia (repeating what was said by others). Even if they can communicate, the communication skills of children with autism are limited to getting needs met rather than information sharing or complex interaction with other people. An individual with autism shows considerable difficulty in using language for communication, interaction, information gathering, and dissemination. This can include delayed development of spoken language and difficulty of holding a conversation (Ruble & Gallagher, 2004).

The communication difficulties, which are various and complex in nature, are categorized into verbal and non-verbal communication. According to Manning-Courtney et al. (2003), the difficulties include complete failure to develop expressive and receptive language skills (as cited Keenan et al., 2007, p. 29). Other difficulties identified by Brook and Bowler (1992) and Rapin (1997) indicated fluent speech with specific semantic or pragmatic impairments among children with autism (cited Keenan et al., 2007, p. 29). Some may have odd pitch, unusual rhythm or stress while others may have a faster or slower rate of speech than normal (Columbia Ministry of Education, 2000). The impaired language characteristic of autism creates a significant barrier to optimal performance on verbal tasks which may impede the ability of a child with autism to complete voice-over tasks.

The communication problems of autistic children extend to their use of non-verbal communication such as avoidance of eye contact, inability to use hand gestures, facial expressions, and repetitive and idiosyncratic speech patterns (Columbia Ministry of Education, 2000). The difficulties in nonverbal communication identified by Tanguay (2000) include profound lack of gestures in communication, inappropriate use of eye contact, and failure to engage in attention sharing behaviors of showing or pointing to objects (as cited in Keenan et al., 2007, p. 29).

Some children with autism have problems initiating conversations and even if they do initiate, they encounter difficulties in maintaining the conversation (Volkmar & Wiesner, 2009). In their words, when children with autism were engaged in conversation, some found it difficult in continuing the conversation. In communicating with a child with autism, the child may repeat words and not fully comprehend how to use the words and phrases effectively (Elliot, 2013). Some children were unable to speak efficiently or might continually discuss one topic again and

again. They also have restricted vocabulary which is dominated by nouns. They use their vocabulary for requests or rejections to regulate their physical environment rather than for social functioning (Ruble & Gallagher, 2004; Volkmar & Wiesner, 2009).

2.3.2.3. Repetitive Behavior and Flexibility Impairment

Children with autism are known for their repetitive behaviors. Some stereotypic and repetitive movements include “flapping hands, rocking, spinning, and finger flicking. The repetitive and restricted behavior displayed by an individual with autism is the result of sensory-motor deficits” (Perry & Condillac, 2003, as cited in Keenan et al., 2007, p. 29). According to Spence et al. (2004), the major repetitive behaviors identified are “opening and closing doors, flipping light switches on and off, and repetitive water play” (Keenan et al., 2007, p. 29). Filipek et al. (2000) and Tuchman (2003) identified finger flicking, hand flapping, body rocking, self-spinning, or running in circles as common motor stereotypical self-stimulating behaviors during preschool years (cited in Keenan et al., 2007).

Concerning flexibility impairment, a child with autism tends to develop particular routines or rituals and may become very disturbed at the slightest change. Elliot (2013) observed seven autistic children and monitored their patterns. One boy in the study, who was named John Y, became very anxious as well as aggressive when his routine was disturbed. Some of the children with autism are fascinated by the details of an object, but cannot comprehend the bigger picture of the subject. According to Wong and Kwan (2010), some children with autism had an unusual interest in food preferences and cravings for chalk and muck, and an interest in unusual topics like telephone directories.

With regards to intelligence, most children with autism are slow to obtain fresh understanding and skills, and consequently have signs of lower levels of intelligence. Some children with autism have normal to high levels of intelligence and are capable of learning quickly (Kamp-Becker et al., 2011). However, they have difficulty in communicating and accommodating, and adapting new information to social situations. A term for such children with autism was known as a savant, that is, a small number of children who had extraordinary skills in art, arithmetic, or music (Elliot, 2013).

Many of the odd and stereotypical behaviors may be caused by other factors such as hypersensitivity or hyposensitivity to sensory stimulation, difficulties understanding social situations, difficulties with changes in routine, and anxiety. Environmental stimuli may be disturbing or even painful to someone with autism (Columbia Ministry of Education, 2000). Children with autism may be remarkably sensitive to light, sound, and touch; however, they tend to be unresponsive to pain (Rubin & Lennon, 2004). Accordingly, children with autism may perform acts that are self-harming such as head banging (Berney, 2004).

Autistic behaviors are a major concern of parents and family. In addition to the behavioral and developmental features of an autistic child, other psychiatric disorders exhibited by children are also of great concern to parents. According to Loveland and Tunali-kotoski (2005), obsessive-compulsive or ritualistic behaviors, hyperactivity/inattention, psychosis, mood disorders or anxiety are the major issues leading to increased difficulty with behavior management, learning, and social relationships.

The child's state is the primary factor behind anxiety and stress among parents with autism. According to Fleischmann (2005), among the most difficult problems that parents

mention are poor language skills; inappropriate and embarrassing public behavior; disruption and destruction in the home; violence and aggression; inappropriate sexual expression, and obsessions with eating and toileting. Higher levels of autism symptomatology are associated with higher reported parental stress (Hastings & Johnson, 2001). The more severe the child's symptoms, the greater degree of parental stress (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). These studies show that social support is very important in combating parents' depression and stress (Fleischmann, 2005).

2.4. Diagnosis and Treatment Options for ASD

2.4.1. Diagnosis

To date, there is no reliable biological marker for ASD. Diagnosis of ASD is based on behavioral observation, parental interview, developmental history, and clinical impression (Dawson & Murias, 2009). Medical and developmental history is taken through discussion with parents. This information is combined with the other assessments to provide an overall picture. Professionals diagnose autism spectrum disorders through the presence or absence of certain behaviors, characteristic symptoms, and developmental delays. The criteria were outlined in the DSM-IV and DSM-V and the International Classification of Diseases/ICD-10 (World Health Organization, 2004).

The “gold standard” diagnostic tools often used in conjunction with the above-mentioned symptoms are the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 2000). The ADOS is a play-based semi-structured assessment of communication, social interaction, and play skills. The ADOS is designed to elicit social and communicative behaviors. There are four different modules in the ADOS. The module utilized is determined by the developmental and language level of the

individual being assessed (Lord et al., 2000). The ADI-R is a standardized caregiver interview used in the differential diagnosis of ASDs (Martinez-Pedraza & Carter, 2009). Although not within the scope of this paper, it is important to note that there are other additional screenings and diagnostic tools available to clinicians screening children for ASD.

Consistent with the change in DSM criteria for ‘autism spectrum,’ the revision of the gold-standard observational measure (ADOS-2) (Lord et al., 2012) emphasizes a dimensional model by including severity scores. This severity index allows clinicians to assess individuals’ entire symptom range and gain important information about symptoms apart from the diagnosis. This dimensional system will also allow clinicians to rate both the presence and the severity of symptoms (American Psychiatric Association, 2013), letting them track improvement and provide documentation about all symptoms. In addition, the diagnostic specifiers used by clinicians lend to a more accurate understanding of individuals’ strengths and weaknesses to service providers across different settings.

2.4.1.1. Reactions of Parents to their Child’s Diagnosis of Autism

The diagnosis process of autism varies from institution to institution and from professional to professional. The diagnostic process includes all the activities in which a clinician engages in trying to understand the nature of an individual’s difficulty (Volkmar, Paul, Klin, & Cohen, 2005, p. 1). NIMH (2011) categorized the diagnosis process in two stages. The diagnosis process begins with general developmental screening with a pediatrician or early childhood care provider. Children identified with the developmental problem in the first stage are referred to the second stage of evaluation for the diagnosis of a child with autism and other developmental

disorder. Nejman (2009) argues for “the requirement of a trans-disciplinary assessment team based on the needs of the child” (p.12).

For parents and caregivers, the diagnosis or evaluation process creates a learning session to acquire advice from the team. On the contrary, diagnostic periods are challenging due to reactions of families. According to Siegel (1996, p. 125), diagnostic debriefing is necessary for some parents to assure the fit between the observations of unusual child behavior and the real entity. The reaction of families to the diagnosis varies from individual to individual. The parents experience a range of reactions to the diagnosis of autism from extreme shock, grief, or denial to relief. Negative and positive (relief) feelings are the common mixture experienced by parents (Ozonoff et al., 2002, p. 52). Upon hearing their child’s diagnosis, a study by Banach, Iudice, Conway, and Couse (2010) found that 52% felt relieved, 43% felt grief and loss, 29% felt shocked or surprise, and 10% felt self-blame.

An initial reaction to hearing one’s child’s diagnosis with autism is denial. No parent wants to know that his or her child can be ‘abnormal’ as society would see it (Davis & Carter, 2008). “Parents’ first reaction to the diagnosis of autism is disbelief, which is a coping mechanism by keeping bad news at an emotional distance from our most inner core” (Siegel, 1996, p. 125). This initial denial is mixed with other emotions that instantaneously placed the entire family unit in a stressful state (Johnson, Frenn, Feetham, & Simpson, 2011). Prolonged denial can prevent a parent from responding judiciously to a particular situation and often hinders the initiation of appropriate timely treatment (Siegel, 1996, p. 128). Knowing that a child is diagnosed with autism, there are challenges parents would have to face such as locating sufficient services to ensure that the child has the best services to meet their needs, emotional problems, physical stress as well as financial problems (Altieri & Von Kluge, 2009). Bashir et

al. (2014a) also stated that at the early stage, parents often feel shame, and fear of discrimination and stigma.

Once parents move from the initial stage of denial, there are other emotions that they experience such as anger, sadness, and loneliness (Rodrigue, Morgan, & Geffken, 1990) before they accept that their child has autism (Gray, 2007). Parents are usually angry and ask themselves, “Why me?” The parent feels unlucky, hopeless, and defeated by the odds as a result of having a child with autism (Siegel, 1996). According to Gray (2007), when these parents of children with autism observed parents of typically developing children, their anger may build up. When parents expressed such anger, it relieved the built-in tension (Jennings, 2005). A suggestion for releasing such anger is informing others of how one feels upon hearing the diagnosis of one’s child is essential (Sanders & Morgan, 1997).

At some point in time, parents typically develop a sense of acceptance. It is crucial to differentiate between accepting that one’s child has autism and being able to accept autism. When the parent accepts the diagnosis, the parent is ready to be an advocate for the child. A study by Capps, Kasari, Yirmiya, and Sigman (2009) suggested that parents must not be harsh, but be patient with themselves, to allow themselves to sufficiently accept the diagnosis of autism, so that they would be better able to assist their children. Once parents have accepted that their child has autism, social supports may help alleviate their stress (Gray, 2007). When parents knew that they had support whether it was through formal assistance such as community programs, religious programs, or informal means from extended families and friends, the level of stress would be manageable and lower (Ekas, Lickenbrock, & Whitman, 2010).

2.4.2. Treatment Options for ASD

There is, currently, no cure for the disorder (Keenan et al., 2007; Myers & Johnson, 2007; Shyu, Tsai & Tsai, 2010). Woodgate, Ateah, and Secco (2008) described it as a chronic, life-long condition. Goin-Kochel, Myers, and Mackintosh (2007) quoted Donald Cohen, “When there is no cure, there are 1000 treatments” (p. 195); this is particularly true for autism. The treatment of autism varies from child to child. Getting a diagnosis of autism is not an easy task. “There is no simple blood or laboratory test to determine who is autistic” (Volkmar & Wiesner, 2009, p. 26). Since the exact cause of autism is not known, the diagnosis mostly relies on observation and history. To accurately diagnose autism, the child should have a comprehensive evaluation by professionals in the fields of language development, behavioral, social, and cognitive skills. Autism is thus diagnosed by a multidisciplinary team that consists of psychologists, neurologists, psychiatrists, speech therapists, social workers, and other professionals (Columbia Ministry of Education, 2000; Ruble & Gallagher, 2004).

Parents and caregivers prefer a diagnosis as early as possible, and there is evidence that suitable early intervention can improve outcomes (Centers for Disease Control and Prevention, 2014). Early implementation of interventions may contribute to a better outcome for the quality of life of a child with autism (Pathappillil, 2011). Similarly, Swanepoel (2003) asserted that early detection is important for early interventions, particularly special needs education is found to develop positive outcomes for the autistic children’s future well-being.

According to a NIMH (2011) study, early intensive behavioral therapy of autism during the preschool years can significantly improve cognitive and language skills in young children with autism. Shreds of evidence indicate that early behavioral and therapeutic interventions can significantly contribute to the life of a child with autism through improving communication,

forming relationships, decreasing maladaptive behavior, and developing independence (Larsson, 2005 as cited in Sharpe & Baker, 2007). The treatment options, indicated by Ozonoff et al. (2002) include “Applied Behavior Analysis (ABA), Treatment and Education of Autistic and related Communication for Handicapped Children (TEACHC), Denver and green span models, social skill groups, educational support, language and communication therapy, functional behavioral analysis, medication, sensory integration therapy, and individual psychotherapy” (p.78).

Over the last few decades, there have been many proposed treatments for autism, with some even daringly upheld as a cure for the disorder. These proposed treatments include “holding therapy, megavitamins, music therapy, auditory integration therapy, facilitated communication, sensory diets, sensory-motor integration therapy, play therapy, gentle teaching, experimental brain surgery, immunosuppressant therapy, and secretin to name a few” (Bodfish, 2004, p. 319). Though there is no specific treatment and medication for autism, the main treatments for autism are educational and behavioral. Other treatment approaches such as medication and alternative methods may be used in combination with these approaches (Swanepoel, 2003). Behavioral interventions which include teaching language and social skills, and decreasing maladaptive behavior are used as therapies and treatments (American National Research Council, 2001; Columbia Ministry of Education, 2000).

Many of these claimed treatments were never promising enough to advance to the rigorous scientific testing found in controlled clinical trials, despite the initial popular media attention bestowed upon them. Furthermore, some of these proposed treatments were even rigorously tested following parent demands to do so and were found to be futile. The proposed treatments were more disappointing chapters in the history of autism treatment because the

treatment approaches have demonstrated that autism is a disorder that seems to be particularly at risk for unfounded claims of treatment (Bodfish, 2004).

Generally, autism has no known cure. Though autism is a lifelong disability that has an impact on not only the individual with autism but also on the parent too, a study by Ben-Itzhak and Zachor (2007) helps to highlight the effectiveness and importance of intensive early intervention, regardless of the severity of the range of symptoms. Additionally, the authors also encourages clinicians to teach imitation skills rigorously in the first stages of intervention, because these skills present an important stage in the process of learning and can be used to teach many developmental and self-help skills.

2.5. Magnitude and Trend of the Problem

ASD is a lifelong disability with no known cure. Autism is one of the developmental problems that affect everyone regardless of culture, race, religion, level of income, or education. Regarding the prevalence of autism among children, in every 10,000-childbirth across the globe, 10 are affected by autism (American National Research Council, 2001; Columbia Ministry of Education, 2000).

The magnitude of autism as a mental health problem can be understood by the prevalence rate. Accordingly, WHO (2013) estimates a global median prevalence is 62/10,000, which is one child in 160 with an autism spectrum disorder and subsequent disability. A year before WHO's (2013) study, Elsabbagh et al. (2012) estimated the global median prevalence rate of autism as to be 1 in 162 individuals. Similarly, WHO (2013) stated the median rate of autism in Europe is 61.9/10,000 (ranges 30.0–116.1/10,000) and in Australia, a half-million individuals are affected by autism.

Although autism affects both sexes, males are more likely to be autistic than females. The ratio ranges from 4:1 to 5:1 (Balfour, 2007). Autism has a spectrum of severity that ranges from mild to severe. The severely autistic individual needs institutional care while the mildly autistic may be very intelligent and can live independently. Approximately one-quarter of people with autism can function in the intellectually normal range and a few may make significant improvements with relative weaknesses in social and communication skills (Balfour, 2007).

In western countries, the average age for an ASD diagnosis is between 4.5 to 5.5 years of age, with 51–91% of these children exhibiting traits before age three (American National Autism Center, 2011; Wiggs, 2010). However, late diagnosis continues to be observed in Africa (Bakare & Munir, 2011; Bello-Mojeeed et al., 2013). According to Bakare et al. (2009), Bakare and Munir (2011), and Bello-Mojeeed et al. (2013), the possible reasons for late identification and diagnosis of autism among African children include poor awareness of the ASD, cultural beliefs, inadequate number of trained staff, and inadequate healthcare and intervention facilities. Conversely, Johnson and Myers (2007) stated that in western countries, the community is more aware of autism because of increased media coverage and an expanding body of knowledge published in professional journals.

Even though autism is a worldwide problem among all races, nationalities, and social classes, according to the American Psychiatric Association (1994), before the year 1994, it affected only four or five in every 10,000 persons. However, research by Mesibov, Shea and Schopler (2005) reported that with a tenfold spike in numbers over the past 20 years, one in every 166 children is now diagnosed with autism. Furthermore, the author estimated, approximately 80% of those diagnosed with autism are boys. The American Psychiatric

Association (1994) stated two children with autism in three remain severely impaired into adulthood and are unable to lead independent lives.

For many years, autism was strongly regarded as a disorder that only exists in developed nations. This created a knowledge gap in developing countries such as Africa and made it difficult to provide a solid prevalence rate about the extent of the problem in most African countries (Bakare & Munir, 2011). In Ethiopia, except for predictions provided by some non-governmental organizations, publications with data about the exact number of children affected by autism are non-existent.

The median estimate of autism syndrome disorder in high-income countries is known to be 62/10,000 (Elsabbagh et al., 2012). However, in most low-income countries, prevalence studies are not undertaken, hence statistical evidence is hardly available (Freedman, 2011; Pottie & Ingram, 2008). To date, a representative community-based epidemiological study on the prevalence, diagnosis, etiology, and treatment of ASD among African children is not available (Bello-Mejeed et al., 2013). Although it is indicated that about 1 in 160 children is diagnosed with autism across the world, in most African countries, it is difficult to estimate the number of children with autism due to the unavailability of statistical data (Nyoni & Serpell, 2012). Comparatively, insufficient attention is given to autism in sub-Saharan Africa. Although a few documented studies have examined the relationship between autistic impairments and the stress on mothers, there is also very little on this subject in sub-Saharan Africa (Bello-Mojeed et al., 2013).

According to the Central Statistical Authority/CSA (2007), the prevalence of disability in Ethiopia is 1.09%. On the other hand, WHO (2011) stated there were 15 million people with

disabilities in Ethiopia. However, the available data do not provide sufficient evidence of the type and prevalence of persons with disabilities by degree and specific category of impairment. According to Tirusew (2005), since the public tends to associate developmental problems with spiritual evil and as caused by one's sins, most of the families do not allow disabled persons to go out in public. This stereotypic attitude also forces families to hide disabled family members, which in turn leads to inaccurate information and statistics on the prevalence of disabilities. Thus, statistical evidence on the extent and prevalence of autism in Ethiopia is not sufficiently available.

According to Getnet (2013), in Ethiopia, there is also a lack of awareness of the existence of autism disorder, and children with autism are deprived of most of their rights and are locked behind doors when parents find it difficult to manage their behavior. Getnet (2013) estimated 0.7% of the total population [600,000 individuals] is living with autism. Similarly, the Nia Foundation (2010) estimated 530,000 people in Ethiopia are suffering from autism and related developmental disorders. Despite the presence of such few studies before a decade, reliable data regarding the prevalence of autism are not yet available in Ethiopia which makes it difficult to trace the magnitude and trend of the problem at the country level.

2.6. Challenges of Autism for Parents

Raising a child with autism spectrum disorder (ASD) can be challenging and overwhelming for parents and families. A child with ASD may require lifelong support and services to improve their ability to function at home, in school, or in the community (Russa, Matthews, & Owen-Deschryver, 2015). The impact of having a child with an ASD can affect parents in several ways, including increased parental stress (Meadan, Halle, & Ebata, 2010), higher levels of mental health concerns (Karst & Van Hecke, 2012), increase in problems within marital relationships (Gau et al., 2011), feelings of anxiety and depression (Factor, Swain, & Scarpa, 2018), feeling isolated and locked at home, as they fear taking their child out in public (Broady, Stoyles, & Morse, 2017), and decreased quality of life for the family (Kheir et al., 2012). In addition to external factors, such as financial costs, the time burden of seeking intervention, and restrictions placed on social activities, can also contribute to parental stress (Lollar, 2008).

Therefore, parents of a child with autism are encircled with several challenges. Hastings and Johnson (2001), Sivberg (2002), and Tarakeshwar and Pargament (2001) explained that the primary concerns and challenges of parents of children with autism include parental depression and anxiety, difficulties in daily management of the child, financial worries, and concerns over adequate educational and professional resources. Dimensions of challenges that parents with autistic children experience are presented below.

2.6.1. Dimensions of Challenges on Parents

Autism has lifetime consequences with a range of impacts on the health, economic wellbeing, social integration, and quality of life of individuals with the disorder, as well as that

of their families. The family has a major role in procreation, caring, nurturing, and socialization. In handling all these responsibilities, families may face many challenges (Sameroff, 1990 as cited in Altieri, 2006, p. 1). The challenges presented in the literature can be best summarized as psychological, social, and financial.

2.6.1.1. Psychological Challenges

The psychological problem of caring for an autistic child places psychological demands on the parent(s) and other family members. Because of the nature of the disorder, economic challenges, and the absence of formal and informal psychosocial support, family members of children with autism experience negative psychological effects. Parents of autistic children were found to be at a higher risk for depression, social isolation, and marital discord (Hailemichael, 2014). Some parents go through periods of disbelief, deep sadness, and self-blame whereas others experience helplessness, feelings of inadequacy, anger, shock, and guilt (Gupta & Singhal, 2005, p. 64). “Parents of children diagnosed with autism also experience greater amounts of anxiety and stress than parents of Typically Developing (TD) children or parents of children with other types of developmental delays” (Dumas, Wolf, Fisman, & Culligan, 1991; Plant & Sanders, 2007 as cited in Plumb, 2011, p. 1).

2.6.1.1.1. Parental Stress

Deater-Deckard (1998) concisely defined parental stress as “the aversive psychological reaction to the demands of being a parent” (p. 315). Parenting stress occurs when one’s perceived resources or the ability of a parent is low compared to one’s perceived demands of parenting, often resulting in negative psychological reactions (Deater-Deckard, 1998). As a challenge to the parent, autism ranks among the most stressful childhood developmental

disabilities. Problems with communication, emotional expression, and antisocial behaviors all combine to place tremendous stress on the families of children with autism (Gray, 2006). In a survey of 219 parents of children with autism, Sharpley and Bitsika (1997), found that more than 80% reported sometimes being “stretched beyond their limits,” with mothers reporting higher stress levels than fathers. They stated that the three most stressful factors are (a) concern over the permanency of the condition; (b) poor acceptance of autistic behaviors by society and, often, by other family members; and (c) very low levels of social support received by parents. On the other hand, the Autism Society (2011) categorized factors that put families in stressful situations into five categories: “Child’s inability to express his/her own need, taking child diagnosed with autism out of the community, the concern of child’s future welfare, parents’ financial aspect and feelings of grief” (Hartmann, 2012, p. 8). Thus, parents of children with ASD report elevated parental stress (Brobst, Clopton, & Hendrick, 2009).

Hastings, Daley, Burns, and Beck (2006) examined predictors of maternal stress in a sample of 75 mothers of children with autism and other intellectual disabilities aged 3-19 years. Although 56% of the mothers of children with other intellectual disabilities reported clinically elevated stress levels, 75% of the mothers of children with ASD were above the clinical cut-off point (Hastings, 2008). Thus, this figure indicates that mothers of children with ASD experience clinical levels of stress more often and of a higher intensity than mothers of children with other disorders. Similarly, a meta-analysis of studies specifically comparing stress in parents of children with ASD to stress in parents of typically developing children demonstrated that the effect size for both was large, 1.58 and .64, respectively (Hayes & Watson, 2013). These findings, along with research demonstrating that the majority of parents of a child with autism estimated between approximately 66% (Tomanik, Harris & Hawkins, 2004) to 70% (Derguy,

M'Bailara, Michel, Roux, & Bouvard, 2016), report significantly elevated stress levels, is concerning.

The child's state is the primary factor behind anxiety and stress among parents. Fleischmann (2005) identified the most difficult problems that parents mention as poor language skills, inappropriate and embarrassing public behavior, disruption and destruction in the home, violence and aggression, inappropriate sexual expression, and obsessions with eating and toileting. Higher levels of autism symptomatology are associated with higher reported parental stress (Hastings & Johnson, 2001). Parents of children with high-functioning autism report significantly higher levels of stress and lower levels of adaptive coping and resources than parents of children with typical development (Lee et al., 2009). The more severe the child's symptoms, the greater degree of parental stress (Dunn et al., 2001).

Parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (Davis & Carter, 2008; Pisula & Kossakowska, 2010).

The feelings of loss of personal control, absence of spousal support, informal and professional support are found to be the major source of stress for parents of children with autism. Other important factors associated with parental stress in families of children with autism include adjustments to the reality of the child's condition, housing, and finance. Families with aggressive and violent children experience a high level of stress in the presence of few resources for treatment or residential placement to deal with the situation (Gupta & Singhal, 2005, p. 63).

Daily stress has been associated with negative mood states (e.g., anxiety and depression) among parents of children with ASD (Pottie & Ingram, 2008). Negative outcomes extend beyond

mental-health concerns (e.g., anxiety and depression) to more general quality-of-life issues, such as parenting competence and limiting the enjoyment that comes from the positive aspects of parenting (Hastings & Johnson, 2001; Rodrigue et al., 1990; Tomanik et al., 2004). The negative impact of stress can also have far-reaching effects on areas outside of the caregiving role for parents of children with ASD, including marital satisfaction, family adaptability, the functioning of siblings, and social isolation (Sanders & Morgan, 1997). Therefore, parents raising young children with ASD are more likely to experience high parental stress and burden, which are associated with a plethora of negative child and family variables. This high level of stress has to be addressed due to its potential negative impact on parents and child development.

2.6.1.2. Social Challenges

Families caring for a child with autism experience several social challenges. Based on families' reports, Gray's (1994) study indicated that society, in general, is resistant to accept children with autism. The low level of probability to receive acceptance from society exposes parents to social stigma and embarrassment associated with inappropriate behavior displayed by their children (Altiere, 2006). Extended family members may also show rejection of autistic children or detach themselves from the family. Schall (2000) explained that relatives of parents with a child diagnosed with autism might be cold, distant, and unhelpful.

Public area attendance is another issue that affects the social life of parents living with a child diagnosed with autism. Since families have a fear of their children's behavior, parents prefer to isolate themselves instead of facing the frustration of taking their child out in public (DeMyer, 1979 as cited in Altieri, 2006, p. 15). Gray (1993) indicated that parents, most commonly mothers and extended family members, experienced severe socializing problems and

frequent social rejection. Findings from the follow-up research also indicate that the majority of parents experienced stigma, with mothers more likely to experience it than fathers (Gray, 2002).

2.6.1.2.1. Stigma

Erving Goffman, a widely cited scholar in the field, defined stigma as “the situation of the individual who is disqualified from full social acceptance” (1963, p. 9). Hence, there is an understanding that a particular individual’s or group’s unique traits have been evaluated and deemed to be discredited by mainstream society (Goffman, 1963). The stigma associated with ASD is significant and enveloping. As a result, Kinnear, Link, Ballan, and Fischbach (2016) suggest the need for research with the parents of children diagnosed with ASD to further understand the components and impact of stigma on their lives.

Parents of children with autism experience stigma from the outside world. They often find that the public’s reaction to them is stereotypical and negative (Gray, 2002). Gray (2002) further explained that the parents of autistic children frequently encounter hostile or insensitive reactions (such as slurs, frowning, unusual staring, and fisting) from the public when their children behave inappropriately. This problem may be exacerbated by the contrast between the children’s appearance, which shows no signs of disability, and their behavior, which is perceived as ‘abnormal’ and strange.

Parents reported that they received criticism from strangers when they were out in public (Farrugia, 2009; Gray, 2002). According to parents’ reports, strangers thought their children were acting out and should be disciplined (Farrugia, 2009). Parents conveyed diverse reactions with regards to the judgment of strangers. In certain cases, parents decided to ignore such

strangers, whereas other parents confronted strangers and/or attempted to educate them about the nature of ASD (Gray, 2002).

Generally, according to Goffman (1963), stigma deeply discredits an individual from a whole person into a tainted, discounted one. Gray and Holden (1992) demonstrated that stigma is linked to decreased wellbeing via increased levels of stress, particularly in social interactions. In supporting this view, Swanepoel (2003) stated that families of autistic children lose friends or isolate themselves because of the public's criticism and inappropriate behavior of the autistic child in public places. As a result, Wachtel and Carter (2008) argue that when a child is diagnosed with ASD, parents experience a range of feelings and a set of challenges that impact their psychological and social wellbeing.

2.6.1.2.2. Challenges on Marital Relationship

As a natural consequence of increased time strain and financial pressure on caregivers, there is a reduction in the quantity or quality of social interactions such as marital, peer, and community relationships. Families with autistic children face many stressors and challenges compared to parents of typically developing children (AlHorany, Hassan, & Bataineh, 2013). Autism is believed to impact the family system by creating difficulty in a marital relationship. The effect of autism on marital relationships can begin with weakening parental bonds or affection. In this regard, DeMyer's (1979) study revealed that more than half of the families in his study had a weak affection/bond with their spouses. The level of marital intimacy of parents of children with autism is lower compared to parents of normally developing children (Fisman, Wolf, & Noh, 1989, as cited in Altieri, 2006, p. 8). Thus, there is a high risk of marital discord among parents of children with autism (Altieri, 2006).

The effect of autism on the marital relationship can lead the family to the extent of conjugal divorce. Several studies (e.g., Brobst, Clopton, & Hendrick, 2009; Freedman, Kalb, Zablotzky & Stuart, 2012; Hartley et al., 2010) found that the increase in parenting stress, conflict, and child problematic behavior contributes to a higher rate of divorce for parents of children with autism than in the families of children with ‘normally’ developing children. Similarly, Vogt (2007) found that parents of children with ASD were less intimate and were at a higher risk for divorce than parents of typically developing children. Parents are forced to put the needs of their children before their own and before the needs of their relationship (Rogers, 2008). Marital discord, lower levels of intimacy, and feelings of diminished spousal support may result in marital dissatisfaction (Benson & Karlof, 2009; Vogt, 2007). Thus, marriages of parents of children with developmental disabilities are sometimes portrayed as difficult, dysfunctional, and particularly likely to end in divorce (Sobsey, 2004).

One of the most significant ways that autism impacts family is by placing additional stress on the parents’ marriage (Hastings & Johnson, 2001; Sivberg, 2002; Tarakeshwar & Pargament, 2001). Newsome (2000) suggested that parents of children with autism have a 9.7% higher chance of being divorced than their peers. The author enumerated how marriage is affected by autism, including inconsistent schedules and numerous commitments, making it difficult for parents to spend time together; challenges associated with finding childcare for children with autism, which also makes it hard for parents to go out as a couple; and financial stresses that can cause additional conflict between parents. According to Lamanna and Riedmann (2000), if parents are not capable enough to handle the situation, they might engage in conflict.

The conflictual relationship between the spouses affects their approach to parenting and the feeling of being supported in stressful situations (Vogt, 2007). The stress of dealing with

autism and all it entails (the constant and necessary advocacy at school, fighting for services and support, added financial burden, trying to handle behaviors and meltdowns at home) becomes a wedge pushing the parents further and further apart (Silice-Kira, 2008). In a similar vein, Lamanna and Riedmann (2000) stated that parents may hesitate to depend on one another for support, may avoid one another, and may start to blame each other for what happened to the family, which affects the marital quality and parents may end up in divorce.

Hartley et al. (2010) investigated the relative risks and timing of divorce in 391 families of children with ASD in a longitudinal study examining the family structure between 1998 and 2004. They used a representative sample of parents of Typically Developing (TD) children to make comparisons. Results suggested that parents of children with ASD had a prolonged period of vulnerability to divorce. Hartley et al. (2010) discovered that parents of children with ASD had an overall divorce rate of about 24% compared to approximately 14% for parents of TD children.

The high burden of caring for an autistic child typically rests on mothers. Patterson, DeBaryshe and Ramsey (1989) indicate the high level of burden on the mother results in marital distress. When the mother is a sole care provider to an autistic child, the attention given to other children is less; less time is given to her and her husband (Altieri, 2006, p. 9). To sum up, having a child with autism imposes an impact and a difficult situation on the marital quality and relationships of the parents.

2.6.1.3. Financial Challenges

The economic impact of having a child with autism is enormous and families with autistic children often experience a strain on their financial resources (Benson & Karlof, 2009; Linares-Gonzalez, 2006; Murphy et al., 2006; Rogers, 2008). Glendinning (1986) indicated,

Most private health insurance plans do not cover all expenses related to therapy and treatment for children with autism, and the payment for office visits and medications often results in huge financial debt. In addition to therapy and medical expenses, there are added economic burdens such as for accessing specialized educational toys, equipment like weighted blankets and vests, and much more (Cited in Hailemichael, 2014, p. 23).

ASD is known to be a costly disorder (New Zealand Ministries of Health and Education, 2008). Autism can place financial strains/challenges on parents in several ways. According to Lavelle et al. (2014), the average annual medical expense for a child diagnosed with autism in 2011 was about \$3,020. This cost was 18% higher than for a child without a diagnosis of autism. The authors further stated the caregiver of a child with autism may face costly prescriptions, emergency room visits, physician office visits, as well as occupational, speech, and physical therapy.

Costs associated with having child with autism are not only limited to the cost of interventions. Like other forms of childhood disability, parents of a child with autism often face greater outlays of time and money (Aadil et al., 2014). Participation in an extracurricular activity for children with autism also puts additional costs on the family. Thus, caring for an autistic child requires more expense in the provision of care, special education, day service provisions, and family expenses as compared to a typically developing child. Jarbrink, Fombonne, and Knapp (2003) estimated that the total cost of raising a child with a disability is “three times greater than

the cost incurred in raising a ‘normally’ developing child” (Keenan et al., 2007, p. 39). Similarly, according to Girdler and Brian (2012), the expense for a child with autism is more than triple that of a child without autism. Their results indicated that the financial costs of caring for a child with ASD can be associated with adverse effects in the lives of families of children with ASD (Jarbrink et al., 2003). Unfortunately, only a few studies have directly examined the costs that families of children with ASD must face, but rather implied the costs that families of children with ASD must pay.

Having a child with autism resulted in an average of a 14% loss in total family income. It is often extremely difficult for both parents to continue working full-time, which means a reduction in household income to go along with the increased expenses, thus leaving them with a reduction in financial resources during a time of increased financial need. Since many parents need a full-time job to access health insurance, loss of full-time employment can have a dramatic and negative impact on the family’s financial situation (McConachie, Randle, Hammal, & Le Couteur, 2005).

The economic concern of parenting a child with autism is very harsh. The cost of caring for a child with autism in Trinidad throughout their lifetime is estimated to be \$3.2 million compared to an estimated \$1.9 million in caring for a normally developing child (Single Fathers Association of Trinidad and Tobago, 2012). The cost is inclusive of medical fees, therapies, special care education, and child-care, which is very demanding. For a single parent in Trinidad, this financial burden can lead to more parental stress and burnout. These expenses are extremely high compared to the general income and cost of living in Trinidad (Single Fathers Association of Trinidad and Tobago, 2012).

Furthermore, in the first attempt to comprehensively survey and document the costs of autism to U.S. society, Michael Ganz, an Assistant Professor of Society, Human Development,

and Health at the Harvard School of Public Health, found that the approximate cost of caring for a person with autism over the course of his or her lifetime is \$3.2 million and approximately \$35 billion a year is spent to care for all people with autism over their lifetimes (Ganz, 2006).

Ganz (2006) broke down the complete costs of autism into two classifications: direct and indirect costs. There are many areas to consider for both classifications. The direct costs can include medical costs such as physician and outpatient services, prescribed medications, and behavioral therapies that are estimated to cost on average more than \$29,000 per person in a year. There are also direct non-medical costs, which include special education, special camps, and child care which is estimated to annually cost more than \$38,000 for those individuals considered to have lower levels of disability and more than \$43,000 for those diagnosed with more disabling levels of autism.

There are also many indirect costs associated with autism. Ganz (2006) explains costs associated with the value of lost productivity as a result of a person being diagnosed with autism. Lost productivity is the difference in prospective income between someone with autism and someone without. Indirect costs also encapsulate the value of lost productivity for the parents of a person with autism. These costs can include loss of income due to reduced work hours or not working at all. According to the author, the estimated indirect costs for individuals with autism and their parents can range from \$39,000 to nearly \$130,000 annually.

Fletcher, Markoulakis and Bryden (2012) interviewed eight mothers of children with ASD to analyze the costs and benefits related to all aspects of the participants' lives. Mothers acknowledged several expenses associated with their day-to-day experiences. For example, they all discussed the changes in their work or financial situations that resulted from raising a child diagnosed with ASD. Common expenses such as treatment costs, special dietary requirements, child-care, private lessons, and cleaning/repairing homes were all mentioned as additional

financial costs these families had to undergo. In addition, mothers mentioned the lack of funds available for family vacations, household renovations, and/or funds for siblings' future educational pursuits. Jarbrink et al. (2003) explained the added financial strain of caring for children with ASD. Costs associated with out-of-pocket expenses and the lack of access (inability) to use formal and informal services were reported as contributing to the strain experienced by the mothers.

With the estimated cost of caring for a child with autism in the U.S., some of the fathers may not be able to provide specialist care for their child and in some cases, the fathers had to quit their job to be full-time service providers for their children (Fletcher, Markoulakis, & Bryden, 2012). The absence of outside work and low levels of employment are correlated with greater degrees of psychological distress, higher rates of despair, apprehension, and resentment (Gray, 2006). Possible indicators of such heightened levels of stress consisted of spending a great amount of time caring for a child with autism, limited adult interaction, and lowered levels of income which are linked to increased economic hardships (Datz, 2008). The stress of time constraints, parental responsibilities, and financial burdens commonly lead to worry about necessary resources and the welfare of the family (Linares-Gonzalez, 2006).

Generally, parents are the primary caregivers of a child with autism and often must bear the social challenges (stigma and discrimination), psychological challenges (stress and anxiety), and economic/financial costs associated with the behavior, treatment, and care (WHO, 2003). It appears that the challenges families face in connection with the developmental disabilities of children are more serious and complicated in developing countries like Ethiopia (Amakelew, Daniel, & Fasikawit, 2000). People with special needs in developing countries have encountered many problems as governments of many of those countries have never committed themselves to provide various services for these large groups of citizens (Getnet, 2013).

2.7. Coping Mechanisms of Parents Raising a Child with Autism

Understanding how parents of children with ASD cope with the daily stressors associated with raising their children is beneficial for many reasons (Pottie & Ingram, 2008), including better parenting of the child and decreasing the unnecessary institutionalization of countless children (Boyd, 2007). Coping mechanisms can be defined as “our efforts to master the demands of stress that include the thoughts, feelings, and actions that constitute these efforts” (Hutchison, 1999, p. 137). Correspondingly, Nabawy and Moawad (2012) pointed out that coping involves psychological and social resources and strategies that help to eliminate, modify, or manage a stressful event. As seen in the previous literature, having a child with ASD creates a stressful situation. How parents respond to the stresses of raising their child with ASD depends on a wide variety of factors influencing their ability to cope.

The age of the parents, number of children, economic status, and their interpretation of the diagnosis of ASD, the family’s sources of support, community resources, and education of the parents are some of the factors that affect the coping mechanisms employed by parents (Durban, Rodriguez–Pabayos, Alontaga, Dolorfino-Arreza, & Salazar, 2012). A previous study by Beresford (1994) illuminated other mediating factors such as family beliefs and perceptions, religious and moral beliefs, overall philosophies and ideologies held by the families, family lifestyles, and the extent of harmony in the family.

An individual’s response to a crisis or challenging situation can be seen in two ways. According to Hutchison (1999), coping efforts may be problem-focused or emotion-focused. Problem-focused coping tries to change the situation by acting on the environment. Situations that are controllable by action are dealt with by focusing on the problem. Emotion-focused

coping functions to change the way the situation is attended to (by caution/avoidance) or the meaning given to what is happening. According to Lazarus (1996), the former refers to coping with the situation by changing the nature of the problem and the latter refers to coping that distracts the attention of the individual affected by a stressful situation. This latter category of coping would be such activities as expressing feelings, praying, and withdrawing. Generally, problem-focused coping strategies are aimed at directly solving the problem or changing the source of stress, and emotion-focused coping strategies are aimed at reducing or managing feelings of distress associated with the stressor. In studies of caregivers, including parents of children with ASD and Intellectual Disability (ID), the use of emotion-focused coping strategies has generally been associated with poorer mental health outcomes among parents, while the use of problem-focused coping methods has often, but not always, been linked to improved parental adjustment (Seltzer, Greenberg & Krauss, 1995).

Coping mechanisms vary from one family to the other (Altiere, 2006). Sivberg's (2002) study demonstrated, parents of a child with autism employed more avoidance coping behaviors (distancing oneself from the rest of the family, relatives, and peers), whereas parents without a child with autism scored higher on self-control, social support, and problem-solving coping mechanisms.

In balancing the functioning of the family system, Gray (2002) found popular positive and negative coping strategies. Support from friends and family members, information-seeking, and participation in religious and individual activities are positive coping strategies. Negative coping strategies include withdrawal from family members, friends, and society (as cited in Altieri, 2006). Similarly, Rodrigue et al. (1990) noted that parents of children with autism frequently use maladaptive coping strategies, like self-blame (as cited in Karst and Van Hecke,

2012, p. 254). Lai et al. (2015) highlighted that the parents of children with ASD used both adaptive (i.e., cognitive reframing; seeking social support) and maladaptive (i.e., avoidance and disengagement) coping strategies, with an inclination towards adaptive coping methods such as seeking social support and positive reinterpretation. Among parents of children with ASD, the use of adaptive coping strategies has also been linked to positive mental health outcomes (Benson, 2006). Encouragement of appropriate coping methods and receipt of social support is recommended as these strategies are found to be beneficial in buffering stress and reducing negative outcomes (Dunn et al., 2001). While promoting adaptive coping, parent can be helped not to employ coping strategies such as withdrawal, self-blame, and avoidance.

There is increasing interest in identifying the factors that might facilitate parents' coping. By understanding parents' positive coping skills, these can be incorporated into parent support interventions. From the reviewed studies, there was no single strategy found to be successful for reducing or coping with parental stress related to rearing a child with ASD. Rather, several coping mechanisms were found to be effective. Some of the common coping strategies in recent literature are described below.

2.7.1. Seeking Social Support

Seeking social support (assistance) is the major coping mechanism that has been found to moderate parenting stress and daily negative mood (Pottie & Ingram, 2008). For example, Mierau (2008) indicated that social supports significantly contributed to reducing family stress and supporting family coherence.

Parents of children with autism need support to assist them emotionally and physically by providing resources (Myers & Johnson, 2007). The primary sources of informal social support

are spouses, partners, neighbors, family, friends, and other parents of children with autism who offer emotional and mental assistance. Formal support, on the other hand, involves local organizations that offer instruction, guidance, and respite care (Myers & Johnson, 2007). Social and spousal supports are extremely important in reducing stress and improving adaptation for families of children with ASD. Social supports, including support groups, appear to be particularly effective in reducing parenting stress and are associated with better mental health (Boyd, 2002; Luther, Canham, & Cureton-Young, 2005). A phenomenological study that explored mothers' perceptions of effective coping strategies for their parenting stressors in the Northeastern United States by Kuhaneck, Burroughs, Wright, Lemanczyk, and Darragh (2010) demonstrated that participation of their spouses in parenting was critical for mothers as significant emotional support. Their study discovered that parents' ability to share the workload with a spouse in particular, was a significant factor in helping them cope with stress. Similarly, Bayat (2007) found working together, communicating, and being flexible were important characteristics in resilient families of children with autism.

Jamaican mothers involved in Mann's (2013) study reported that having social support helped them to attain needed information regarding the spectrum and to reduce their stress by sharing it with professionals and other mothers who have a child with autism. In the same way, Altieri (2006) demonstrated that families in his study relied on other parents of autistic children for support and that they gained valuable friendships with other parents of a child with autism. Generally, many parents stated that meeting other parents of children with ASD was beneficial to help them feel less isolated and believed that these strategies should be put in place (Murphy & Tierney, 2007). Studies by Gray (2002), Boyd (2007), Pottie and Ingram (2008) and Dardas

(2014) found that parents of children with ASD who have a strong social support network demonstrated a greater ability to cope and adapt to new and challenging situations.

2.7.2. Coping through Religion

Participation in religious organizations was another positive coping strategy (Gray, 2002). Several families found extensive support by religious organizations and felt that their spirituality was enhanced because of their situation (Altiere, 2006; Nyoni & Serpell, 2012). Wiggs (2010) showed that being involved in a Bible study assisted the participants in developing patience, managing stress, and dealing with the obstacles that come with their child's autism. Similarly, Durban et al. (2012) found that parents were able to find comfort in religion because it could give them the strength to continue their lives despite the challenges they faced with the extra burden of taking care of a child with ASD.

Dardas (2014) showed that positive reappraisal and spirituality were the most commonly used coping strategies among Jordanian parents raising a child with autism. Dardas further argued that the use of positive reappraisal as a coping strategy might be due to the Jordanian culture in which one needs to believe in God's will and pray to bring comfort and calm.

2.7.3. Acceptance and Cohesion

Using a phenomenological study, Mierau (2008) found that when parents find out their child has autism, they immediately experience a sense of loss, grief, and face other negative impacts. However, acceptance and understanding helped them to recover from their grief.

Families who have moderate levels of cohesion show higher levels of positive coping (Altiere, 2006). Balfour (2007) stated that for mothers in his study, a positive attitude and

acceptance of the autism diagnosis were important aspects of getting through the day or coping, which enabled them to find appropriate interventions and education for their children. Similarly, Jardine (2008) demonstrated acceptance was an important part of these parents' experiences that facilitated their ability to cope. For the parents in Jardine's study, acceptance involved being able to accept and adjust to the additional issues that come along with autism. This was essential, despite ASD not being a condition that will go away and indeed, requires ongoing adjustment as per the challenges/needs.

Finally, Sivberg (2002) agreed that a strong sense of cohesion and acceptance had a stress-reducing effect regardless of a severe life situation. Parents in this study reported developing adaptability as they educated themselves and learned new strategies to create a cohesive family unit. To conclude, from the above studies one can infer that accepting and/or understanding the situation, and having a cohesive, coherent, and harmonious family could help the parents to cope better.

2.7.4. Knowledge and Information

Information about specific areas of impairment associated with the burden of care in autism could inform the design and implementation of appropriate interventions to help parents understand and cope with the behavior of a child with autism (Bello-Mojeed et al., 2013). Mierau (2008) indicated that parents experienced a sense of relief when having knowledge and information about autism. Educating themselves about autism helped parents to better understand their children's behavior and to plan for the future. Sivberg (2002) and Kuhaneck et al. (2010) suggested that parents need to fully increase their knowledge about the phenomenon of autism to

effectively manage the upbringing of their child. Knowledge equals power and can motivate parents to be the greatest asset to their children.

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

In their study of parents' need for information and education about autism in Ireland, Murphy and Tierney (2007) indicated that parents used the information to gain a greater sense of control over child and family outcomes. The majority of parents reported that other parents of children with autism and the internet were their greatest sources of information and emotional support. Similarly, South African mothers in Balfour's (2007) study demonstrated that increased knowledge and information about autism enabled them to get through each day with a feeling of resiliency and a sense of commitment to their children. Generally, the above literature indicates that social support, religion, information, acceptance, and cohesion are positive coping mechanisms used by parents of children with autism to deal with the challenges of raising their children.

2.8. Available Supports for Parents of a Child Living with Autism

“Parenting autistic children is the most demanding and challenging task that creates physical and emotional exhaustion. Many parents greet the news with shock and denial and keep looking for ways to prove it is not true. At the same time, they often experience tremendous guilt and anger. After passing the first stage parents cope with the situation

differently. One parent may cope by giving every attention for the child and others may become avoidant or depressed” (Volkmar & Wiesner, 2009, p. 28).

Raising a child with a disability introduces challenges throughout the life cycle for the child as an individual, the parent, and the family as a unit. To cope with these challenges, support must be provided. Freedman and Boyer (2000) specifically looked at social support through a family supports perspective in the context of developmental disabilities. They defined social support as “services, resources, and other types of assistance that enable individuals with developmental disabilities of any age to live with their families and to be welcomed, contributing members of their communities” (p. 59). On the other hand, Dunst, Trivette, and Cross (1986b) defined social support as a multidimensional construct that includes psychological, physical, educational, and instrumental assistance. Social support may refer to formal services such as those received from professional organizations, or informal support from friends and family (Boyd, 2002).

The present study examined the formal and informal support that may be available to families with children (Boyd, 2002). Formal social support is the assistance that parents receive from an organized group or agency, and informal social support is the support that parents receive from “the immediate and extended family, friends, neighbors, and other parents of children with disabilities” (Schopler & Mesibov, 1984, p. 297), and may involve psychological, physical, or financial support (Boyd, 2002). Formal support, as understood and used in this dissertation is provided by professionals, organizations, healthcare providers, counselors, therapists, respite care personnel, and schools (Boyd, 2002). Informal support would come through parental networking and may include support provided by family members, parent support groups, friends, and neighbors (Boyd, 2002; Renty & Roeyers, 2006).

Both formal and informal social supports have shown significant positive effects on parental stress in the United States (Estes et al., 2013; Singer, Ethridge, & Aldana, 2007). It is suggested that parents of children with autism who use some form of social support (be it formal or informal), are at reduced risk for stress and mental health problems compared to parents who do not (Zablotsky, Bradshaw, & Stuart, 2013). Similarly, a study of 172 parents of children with autism demonstrated that both fathers and mothers who reported receiving more social support had lower levels of depression, anxiety, and anger (Gray & Holden, 1992). Low levels of social support have also been identified as powerful predictors of anxiety and depression in mothers of children with autism (Boyd, 2002).

Siklos and Kerns (2006) identified fundamentals that family support should embody. According to their study, services should both enable and empower parents to make informed decisions regarding their disabled child, be open to the needs of the entire family, and be flexible in accommodating the unique needs of individual families. By and large, to assist the parents in coping with the disorder, support systems have to be established and provided based on the needs of each parent.

As Bronfenbrenner (1986) conceptualized, it is important to consider the individual needs of each family when determining what support is required. Gupta and Singhal (2005) indicated that “cultural values, financial needs, available resources, the severity of the disability, level of social support, family structure and geographic location are all variables to consider in designing and implementing effective family support” (p. 74). The authors also stated that all or any of these variables could enhance or limit the effectiveness of the support and highlighted the need for individualization. For example, low-income, single-parent families would have different

needs, sources of stress, and/or available resources than affluent two parent families. Thus, the level and type of support should fit the needs of the individual family.

According to Gropman and Batshaw (2010), to cope with the challenges of raising an autistic child, parents need professionals' advice, information, and support. Meron (2006) similarly argued that parents of children with autism need professional support to cope positively with the disorder. Gupta and Singhal (2005) stated that most parents of autistic children need psychosocial and informational support as well as access to professional services, respite care, and financial supports.

2.8.1. Psychosocial Support

Families living with a child diagnosed with autism are at risk of experiencing social and psychological impacts and crises. To ensure the provision of psychosocial support for parents, the concerned governmental and non-governmental organizations need to act. According to Fischer and Corcoran (2007), "social support is an important buffer against family crisis factors and be a factor in resiliency promoting family recovery, and as a mediator of family distress" (as cited in Plumb, 2011, p. 18).

Psychological or social support can take the form of formal or informal support. Schopler and Mesibov (1984) define formal social support as assistance that is social, psychological, physical, or financial and is provided either free or in exchange for fees through an organized group or agency. Informal support is a network that may include the immediate and extended family, friends, neighbors, and other parents of children with disabilities (cited in Plumb, 2011). Formal supports systems are perceived to be given by professionals and informal support systems are given by family members, friends, and through membership of social groups that are

integrated into the family's daily life. Formal support resources include family therapy, family education, professional advice, and counseling.

Parent Training/Education: Parent training is also referred to as parent education which “broadly refers to program or training designed to provide parents with information or teach them skills” (Schultz, Schmidt, & Stichter, 2011, p. 96). Historically, parent stress has been targeted through a variety of parent training programs.

Although improvements have been made to services offered to families with autistic children, few of those services address the emotional stress parents of autistic children face daily. Parents must have access to much support to help them feel more confident and to prepare them in facing the challenges that being a parent to an autistic child entails. Therefore, a group providing parents with essential coping skills must be an essential part of a family treatment program (Linares-Gonzalez, 2006, p. 31-32).

It appears that support groups for parents of children with ASD can offer them the information, understanding, and acceptance they need. Woodgate, Ateah, and Secco (2008) explained that 14 parents experienced extreme social isolation and lack of understanding from others as a result of having a child with ASD. This finding proposes that a crucial need of parents of children with ASD to cope with their child's diagnosis is to find acceptance and support by others. Counseling and therapeutic services have also been offered to parents of children with ASD. The different treatment modalities include cognitive behavioral therapy (Feinberg et al., 2014), relaxation therapy (Gika et al., 2012), and acceptance and commitment therapy (Kowalkowski, 2012).

On the other hand, parents of children with ASD have been able to access support through family members and friends, which has been referred to as ‘informal support,’ in the form of material (buying foods, clothes or gifts), and non-material support (information sharing, understanding, helping in domestic chores, personal advice, or praying), providing transportation services, and financial support (Boyd, 2002; Dunst et al., 1986b; Siklos & Kerns, 2006).

Studies have generally shown that support from services may well be useful for parents. For example, a study conducted by Hastings and Beck (2004) showed that typical appropriate supports provided by services for children with intellectual disabilities and their families made some contribution to the reduction in parental stress. These supports included consultation with professionals and direct service from professionals to the child with the disability.

In the provision of assistance, both formal and informal supports have significant contributions. However, Herman and Thompson (1995) found that based on parents’ reports, informal supports provide the most assistance [are largely accessible], while formal support opportunities, such as social clubs and daycare centers were not available in most cases (cited in Plumb, 2011). Gray and Holden (1992) indicate that mothers who received higher levels of informal and formal social support reported lower levels of depression, anxiety, and anger (as cited in Plumb, 2011).

2.8.2. Financial and Respite Support

Parents or caregivers of children with disabilities may benefit from concrete services such as stipend programs (payment for financially challenged) and respite care. In a study of a cash subsidy program, Herman (1991) found that parents rated the cash subsidy as helpful, as improving their overall family life and ability to care for their child with a disability, and as

enabling them to receive more respite care and professional services due to the subsidy. Similarly, Meyers and Marcenko (1989) found that cash subsidies reduced family financial stress and led to fewer families anticipating out-of-home placement. Chan and Sigafos (2001) reported that respite care reduced short-term stress for mothers and had a particularly positive effect on mothers of younger children. Herman and Marcenko (1997) found that respite care had an indirect effect on maternal depression mediated by the adequacy of time and adequacy of childcare resources. When mothers received respite care, they felt they had more time and adequate babysitting resources. These more positive perceptions, in turn, led to a decrease in maternal depression. Since mothers bear the brunt of the economic impact of having a child with a disability, it is not surprising that stipend and respite care programs would be particularly beneficial for them (Herman & Marcenko, 1997). While parents frequently reported that respite care was a strong need, they indicated that rarely was that need met (Bromley et al., 2004). Siklos and Kerns (2006) found that all the parents in the study felt that the services being provided were inadequate. Parents of children with ASD expressed significantly less satisfaction with the services they received, and 93% expressed inadequate financial assistance. Support received was expressed to be more crisis management rather than proactive. Herman and Marcenko (1997) also claimed, although concrete services are beneficial to parents, they are often underfunded and difficult for parents to access.

In summary, raising a child with a disability has been shown to create higher stress in parents as compared to parents raising a neurotypical child. Moreover, research has shown that raising a child with autism generates exceptionally high levels of parental stress (Davis & Carter, 2008). Both formal and informal social support has the potential to act as a buffer against elevated levels of stress (Benson, 2006; Boyd, 2002). There is a body of literature that shows

formal support, more often than informal support, is associated with reduced parental stress (Gray & Holden 1992; Hastings & Beck, 2004). Results from such studies indicate that support from professional agencies such as therapists and pediatricians is a stronger buffer against parental stress than the support that comes from a parent's family and friends. Understanding the sources of support that are the most beneficial to parents is vital to supporting parents raising a child with autism. To that end, the current study was able to show the correlation between parental stress and both formal and informal supports. Thus, the present study investigated how social support, both formal and informal, affects parental stress levels while raising a child with autism. The focus and format of the support parents receive has the potential not only to assist them in meeting the challenges they confront in their personal lives but can also impact the methods they adopt in parenting their children with ASD (Robert, Leblanc, & Boyer, 2014). Therefore, the question of what constitutes effective support for parents of children with ASD are important to examine from the types of support models typically implemented with these parents and any existing evidence of the effectiveness of the models from the literature.

2.9. Tips for Parents and Practitioners on how to Cope with ASD

The specific conditions that contribute to higher stress are not always agreed upon in the scientific literature (Grant & Whittell, 2000). According the authors, while some studies show that severity of ASD contributes most to stress; others show that these static conditions are not in themselves factors that influence stress associated with parenting and caregiving. Grant and Whittell (2000) suggest that the well-being of these parents depends not on static conditions but on dynamic conditions that are related to their situation, which often can be changed. These conditions include the accessibility and availability of resources to help parents with their parental responsibilities (Davis & Carter, 2008; Kuhaneck et al., 2010; Weiss, Wingsiong, &

Lunsky, 2013). Dynamic conditions include the use of positive cognitive reframing (Hastings 2003; Marshall & Long, 2010), parents gaining access to perceived greater social support (Gray, 2002; Kuhaneck et al., 2010), and parents' ability to plan ahead of their schedule (Kuhaneck et al., 2010; Weisner, Matheson, Coots, & Bernheimer, 2005).

Planning and having a consistent or at least predictable routine is the typical advice offered to parents of children with autism. While little is known about the effectiveness of family-based planning, Weisner and colleagues (2005) have found that sustainability of routine was an important outcome for families and one which varied greatly between families of children with a disability. Examining the efficacy of planning for family functioning may be an important avenue of research in the future.

Sivberg (2002) studied strain on the family system and compared the coping behaviors of parents of children with ASD with those of parents with non-ASD children. The results supported the hypothesis that there are differences in the types of coping behaviors employed. The parents with a child with ASD scored higher in coping behaviors of distancing and escape, behavior aimed at withdrawal from a stressful situation. The parents in the control group, in contrast, scored higher in the use of self-control, social support, and problem-solving. The family's perception of stressful experiences also affects family coping strategies. The use of reframing as a coping strategy was elucidated as a possible way of successful coping (Luther et al., 2005). Redefining personal goals, family goals and priorities and reframing helped the families cope with autism.

2.10. Previous (Empirical) Studies on Autism in Ethiopia

There are a few empirical works on autism in Ethiopia. Wajira (2014) investigated the dominant autistic behavior among school children in Jimma Town. In his study, he attempted to use different developmental traits against the DSM-IV diagnostic criterion and checked for (1) presence of symptoms at an early developmental period, (2) developmental impairment in three areas, including impairment in social interaction, communication, and repetitive behaviors. The study showed that the prevalence of autism spectrum disorder is estimated to be 33 of 10,000 school-age children.

Fisseha (2012) conducted a study to explore the lived experiences of mothers of children with autistic disorder and their reactions to the diagnosis of autism. Her research site was Nehemiah Autism Center. An interpretive phenomenological research strategy was employed and data were collected from six participants using in-depth interviews. The findings showed that before the diagnosis of autism, the mothers noticed peculiar behaviors in their children. This period is characterized by confusion and rationalization of the behaviors. The study also revealed that mothers suspected or knew that there is something wrong with their child, which ofcourse, was refuted by professionals. Mothers' reactions to the disclosure of results of the diagnosis include being shocked, crying, anger, disappointment, and a feeling of loss of the child. Most of the participants did not receive adequate information about autism and treatment options until they went to Nehemiah's Autism Center, even from professionals who diagnosed their children.

Efrem (2005) studied the role of parents of children with autism in early intervention programs in Addis Ababa. This research was established from the fact that the parental role is especially important in the process of assessment, program planning, and implementation of educational and other training packages to improve the life situations of children with autism. The research mainly focused on examining the role played by the parent of children with autism

in early intervention programs. Most of the participants (parents) in this case study indicated, they have a positive attitude towards the intervention strategies for autism. The extent of direct involvement of parents in teaching their children with autism seems to vary according to the educational and socio-economic status of the parents. In general, parents of children with autism are not using enough teaching and playing materials and are practicing the teaching process at home. The study suggested parents need training and counseling on the consequences of autism and relevant treatment techniques.

Using qualitative methods, Meressa (2014) studied the learning problems of children with autism and the challenges in the teaching process. The results of the study showed that children with autism have learning problems related to their social behavior, communication, and insistence on the maintenance of sameness. Teachers face challenges in managing the behaviors of the children, especially repetitive and stereotypic behaviors in the teaching process. Lack of parents' cooperation was another challenge mentioned by the teachers. The study revealed that teachers employ visual methods, storytelling, and reinforcement as the main techniques in teaching the children.

Salem (2016) conducted a quantitative study to assess the knowledge and attitude of nurses towards childhood autism at selected governmental hospitals in Addis Ababa. Data were collected using structured self-administered questionnaires from 360 nurses. The results show that 54.35 % of the nurses have good knowledge of autism and its treatment. The age of respondents, level of education, and work experience have a significant association with the nurses' level of knowledge about childhood autism. Regarding the attitude of nurses, 53.8 % have a positive attitude towards working with autistic children. Salem (2016) suggested improving the knowledge and attitude of nurses towards childhood autism to provide quality care for autistic children.

2.11. Theoretical Framework

2.11.1. Explanatory Theories of Autism

A theory is “an abstract system of concepts that helps to understand the phenomenon and serves as a lens to interpret specific concrete experiences” (West & Turner, 2010, p. 44). The theoretical framework is the foundation from which all knowledge is constructed (metaphorically and literally) for a research study (Grant & Osanloo, 2014). Scholars have examined ASD from biological and psychosocial perspectives in their search for the cause, nature, and treatment.

Several theories put forward to explain the causes of autism have formed the basis of the popular understanding of autism in the public and in the scientific community. Although some of these theories have changed or have been abandoned by the scientific community, they contribute to the lingering ideas in the popular understandings of autism and may be responsible for some of the misconceptions that have persisted. Five main theories are briefly discussed here in this section.

2.11.1.1. Refrigerator Mother Theory

In the early years of awareness of autism in the mid-twentieth century, autism was believed to be a solely psychological condition with no organic—that is, physical or neurological—basis. Originally, it was believed that the cause of autism was purely environmental, with specific blame laid on a mother’s failure to bond with her infant. For example, the term “refrigerator mother” was used to describe those mothers whose complete lack of appropriate nurturing of their infants in early childhood led to autism (Bettelheim, 1967). A child psychologist Bruno Bettelheim, in his 1967 book, “The Empty Fortress,” argued that

autism was caused when a child withdrew from the unbearable rejection of a cold, unresponsive mother. This mother, it was suggested, had not wanted the child before the delivery which continued even after delivery, whether consciously or unconsciously.

This view of autism was very destructive and placed a terrible burden of blame on the mother who was already devastated by her child's condition. In making things worse, when anyone studied families or parents with an autistic child, they found the mothers were depressed, stressed, overwhelmed, and not very available, all of which was interpreted as a claim for the refrigerator mother theory rather than the impact of the child's condition on the mother.

It appears that this theory and its proponents had a narrow view of the interactions of mothers with children, attributing the cause of autism to the mother's inadequate communication and synergy with her child. However, this explanation conveniently ignored the fact that in most cases there is a lack of reciprocity from the child's side towards the mothers' cues.

2.11.1.2. Genetic Theory (GT)

Unlike the refrigerator mother theory, Kanner suggested that autism has a genetic component. According to Rutter et al. (1999), findings from several independent studies provide compelling evidence for a strong genetic component underlying autism. Richard (2010) stated if one member of a twin pair is autistic, the probability that the other will also be autistic depends to a significant degree on whether they share all their genes or only half their genes (the same as ordinary siblings). Rutter et al. (1999) indicated autism is the most strongly, genetically influenced of all multi-factorial child psychiatric disorders.

2.11.1.3. Theory of Mind and Mind-Blindness

It is argued that the ability to understand others' point of view—their beliefs, motivations, and goals—is essential, for successful social interaction. The phenomenon, termed 'mentalising', has been called the Theory of Mind (ToM) (Frith & Happe, 1994). Though the term "Theory of Mind" (ToM) was first used by Premack and Woodruff in 1978, this theory has been developed in relation to autism most notably by Baron-Cohen (1990, 1995), and Frith & Happe (1994). In their studies, they affirmed that there is an association between individuals with autism and deficits in ToM (using both clinical trials and neurological testing).

The ToM hypothesis, or mentalising, has become one of most influential theories of ASD over the past 30 years (Frith & Happe, 1994; Simmons et al., 2009), positing that individuals with autism have difficulties in predicting and explaining the mental states of others (Baron-Cohen, Leslie, & Frith, 1985; Simmons et al., 2009). Thus, according to Kirk (2014), ToM enables human beings to understand the thinking and feelings of other people. This theory of autism maintains that what all-autistic people have in common (the core deficit) is 'mind-blindness' (Baron-Cohen, 1990). Mind-blindness is a severe impairment in their understanding of mental states and in their appreciation of how mental states govern behavior (Baron-Cohen, 1995). Autistic individuals fail to develop the ability to attribute mental states to other people and this has fundamental implications for communication, in which making sense of others' intentions enables the listener to understand what is being said (Baron-Cohen, 1995). The strongest evidence for a lack of a theory of mind (ToM) and mind-blindness among children with autism is their consistent failure on false belief tasks, in which participants are required to infer the mental state of a person from another person's point of view (Baron-Cohen et al., 1985), while 'normal' or typical children reliably pass them (Richard, 2010). Non-autistic individuals

can ‘mind-read’ easily and naturally. The author further stated that individuals with autism may become distressed by changes in their immediate ritualized behaviors and they do not plan to anticipate the consequence of their actions. According to Senju (2012), this form of ‘mind-blindness’ is thought to account for social and communication impairments.

Generally, the strength of this theory lies in its ability to make a connection between a person’s impairment in understanding the mental states of others, and their difficulties with social interactions and communication. However, a criticism of the mind-blindness approach is that, it fails to account for the non-social characteristics of ASD, such as obsessive behaviors and/or sensory problems.

2.11.1.4. Stress and Coping Theory

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) provides an appropriate theoretical perspective for studying stress and coping among parents of children with ASD and is perhaps one of the best-known theories of coping. The transactional model originated in the 1960s when a group of researchers headed by Lazarus and Folkman attempted to understand and describe stress and coping (Beresford, 1994). Beresford (1994) notes that since the mid-1980s, the model has been widely adopted and recognized as the most inclusive theory of stress, adjustment, and coping.

Parenting stress can primarily be understood utilizing the fundamental theory of stress proposed by Lazarus and Folkman’s Transactional Model of Stress and Coping (1984). According to the model, “the stress [or parenting stress] occurs in the context of four interacting processes: (a) an external causal event; (b) parental cognitive appraisal of the event to determine whether it is harmful or not; (c) coping mechanisms to reduce the noxiousness [harm] of the

event; and (d) consequential effects on the mind and body (the stress reaction)” (Deater-Deckard, 1998, p. 316).

Lazarus and Folkman (1984) described coping as a process in response to situations in which internal and external demands may exceed the individual’s resources. Folkman and colleagues (1986) determined that there are two major functions of coping. The first function of coping is trying to make sense of the stressor/problem, and the second function is to regulate the emotions that are occurring because of the stressor. Lazarus and Folkman (1984) explained that coping depends on cognitive processes, particularly, primary appraisal (what is the challenge?), and secondary appraisal (what are my options?). These initial cognitive processes portend coping strategies and behaviors that affect adjustment to the stressor.

Pearlin and Schooler (1978) define coping in their influential article, ‘The Structure of Coping’ as “any response to external life strains that serve to prevent, avoid, or control emotional distress” (p. 3). They describe three possible avenues that protect against life stressors: 1) eliminate or modify the situation to prevent the rise of the problem; 2) perceive or interpret the situation in a way that neutralizes its negative characteristics, or 3) work to manage the emotional consequences to prevent being overwhelmed. Pearlin and Schooler further stated that a person’s coping repertoire can include psychological resources, social resources, or specific coping responses such as behaviors, cognitions, and perceptions. “Psychological resources are the personality traits that enable people to mediate or endure stress, such as positive affect; social resources are those found from family, friends, neighbors, and parent groups that support and guide; and specific coping responses are ‘the things that people do’ to avert” (p. 5). Stress theory has contributed to conceptual models that describe the active processes and adaptation that builds resilience.

Stress and coping theory illustrates how a parent dealing with challenges will “marshal its resources and focus its perceptions on positive aspects of its life” and become a catalyst for improved family functioning (Summers, Behr, & Turnbull, 1989, p. 30). Furthermore, the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) is used to understand and frame the experience of stress and coping among parents of children with ASD. Understanding this model could be valuable in developing supportive interventions in order to reduce the negative impact on parents when confronted with an acute crisis or challenge.

2.11.1.5. Family Resilience Theory

Family resilience theory has evolved and has been influenced by numerous assumptions of stress and coping theory and an abbreviated overview of those propositions, principles, and concepts that follows the theory (Luthar et al., 2006). The concept of resilience has roots in two bodies of literature: the psychological aspects of coping, and the physiological aspects of stress (Tusaie & Dyer, 2004). According to Greene (2006), the study of resilience has emerged and grown out of the ‘discipline of epidemiology’. Early developmental theorists recognized the importance of studying both atypical and normative development as a way to better understand human functioning and adaptation. The study of resilience stems from the empirically-based knowledge of human behavior and contributes to the social work profession’s strengths-based philosophy of care and counseling (Greene, 2006). This theory builds on a competence-based and strength-oriented family paradigm that allows a greater understanding of how families display resilience (coping) when challenged by adversity (Walsh, 1998; 2003).

Though there is some variation in how researchers conceptualize and define personal resilience, most definitions are uniform in referring to an individual’s ability to lead a more

successful life than expected in the presence of adversity (Brooks, 1994). Resilience refers to a person's capacity to navigate through life regardless of harsh conditions or misfortune in part by making the necessary adaptations to maintain equilibrium (Alvord & Grados, 2005). Masten (2001) describes resilience as a "class of phenomena characterized by good outcomes despite serious threats to adaptation or development" (p. 228). Luthar, Cicchetti and Becker (2000) describe resilience as a dynamic process encompassing positive adaptation within the context of significant adversity. Gordon (1995) defined resilience as the ability to flourish and mature, as well as increased ability and skills in the face of adverse situations. Parents of children with ASD are faced with a great deal of adversity in their daily lives. When they rise above these challenges and continue to develop a healthy adaptation despite their difficulties, they can be considered resilient.

Resilience within families affected by autism is not yet a well-researched area but it can assist in exploring why some people cope well with stressors while others do not is a fascinating concept (Heiman, 2002). One's ability to cope or be seemingly resilient is an admirable quality and identifying how they did is of great importance if others wish to emulate their success (Mundy & Sigman, 1989). It is important to identify elements that enable families to cope effectively and emerge from a crisis or from persistent stress. For decades, some family researchers have been interested in finding out why some families facing adversity manage to function well and come out stronger, while others faced with a similar situation do not (Patterson, 2002; Walsh, 1996).

Bekhet, Johnson, and Zauszniewski (2012) reviewed 58 research articles on raising a child with ASD and found that 22 of the articles included indicators of resilience. Examples of these indicators include self-efficacy, acceptance and sense of coherence, optimism, and positive family functioning, such as commitment to sharing responsibilities, communicating, having a

positive outlook and relationships, and exercising spirituality. The authors asserted that parents who possess the indicators of resilience were better able to manage the stressors associated with raising a child on the autism spectrum. Similarly, Heiman (2002) lists the contributing variables of resilience as, a successful adjustment in terms of self-esteem, social support, problem-solving skills, well-defined faith, coping skills, interdependence, and the ability to reframe barriers and obstacles. Furthermore, the author claimed these characteristics enable parents to function and maintain their confidence and optimism during times of crisis and allow positive coping.

O'Brien (2007) attributes resilience in families affected by autism to flexibility. Learning that the child has a lifelong developmental disorder is stressful and challenging to any family, yet it is clear that some families adapt and adjust more readily than others and that their resilience comes from their malleable qualities and learning to live with uncertainty (O'Brien, 2007). A family is resilient when it demonstrates strength, even if it may not demonstrate the same attribute at another point in time (Walsh, 2003). Several key factors that contribute to a family's becoming resilient are: (1) making meaning of adversity, (2) affirming the strength and keeping a positive outlook, and (3) relying on spirituality and a belief system (Walsh, 1998). In addition, for a family to rebound in the face of a challenging situation, the family needs to possess certain organizational qualities, such as flexibility, connectedness, communication, and the ability to utilize resources (Walsh, 2003).

The family resilience framework developed by Walsh (2003; 2006) improves our conceptual understanding of the key family processes that can manage current and future environmental stressors. This framework contains three key themes, each with three subthemes (See Figure 1). Family belief systems encompass how a family makes meaning of adversity, their positive outlook, transcendence, and spirituality. Organizational patterns include a family's

flexibility, connectedness, and social and economic resources. Communication processes include clarity, open emotional expression, and collaborative problem-solving.

Family Belief Systems

According to Walsh (1998), family belief systems include values, attitudes, biases, assumptions, and concerns. Humans live in the context of communities that are influenced by the larger social context. Among other factors, resilient families are those whose belief systems allow them to make sense of a crisis or event that they would not consider typical. By normalizing the experience, families can make it manageable and meaningful, and can use it to strengthen family coherence. Families that remain optimistic about the future during a crisis actively seek the tools needed to maximize a successful outcome.

Family Organizational Patterns

Walsh (1998) asserts that families need to organize themselves, particularly during challenging times. This organization often provides a level of stability and comfort, establishing a foundation of trust that allows connections with outside resources and supports. Resilient families often have age-appropriate family rules that are acknowledged and predictable (Black & Lobo, 2008). Walsh (1998) notes that family relationships change over the course of the lifecycle, emphasizing that families must continually assess their current level of connectedness to ensure that each family member's needs are being met. While Olson (2000) acknowledges that families tend to prefer stable and orderly patterns, they often function best when a balance is achieved between moderate amounts of structure and flexibility.

Other important components of family organizational patterns include social and economic resources. During times of adversity, resilient families can tap into their social and professional networks for concrete financial, educational, and therapeutic resources.

Communication/Problem Solving

Clear communication is vital to family resilience. As Walsh (2003) states, “clarity and congruence in messages facilitate effective family functioning” (p. 12). This concept works hand-in-hand with open emotional expression. Families that can share feelings empathize with each other’s unique experiences. Positive interactions and feelings of connectedness provide strength for coping, and resilient families demonstrate the ability to brainstorm potential ways to approach a problem (Walsh, 1998).

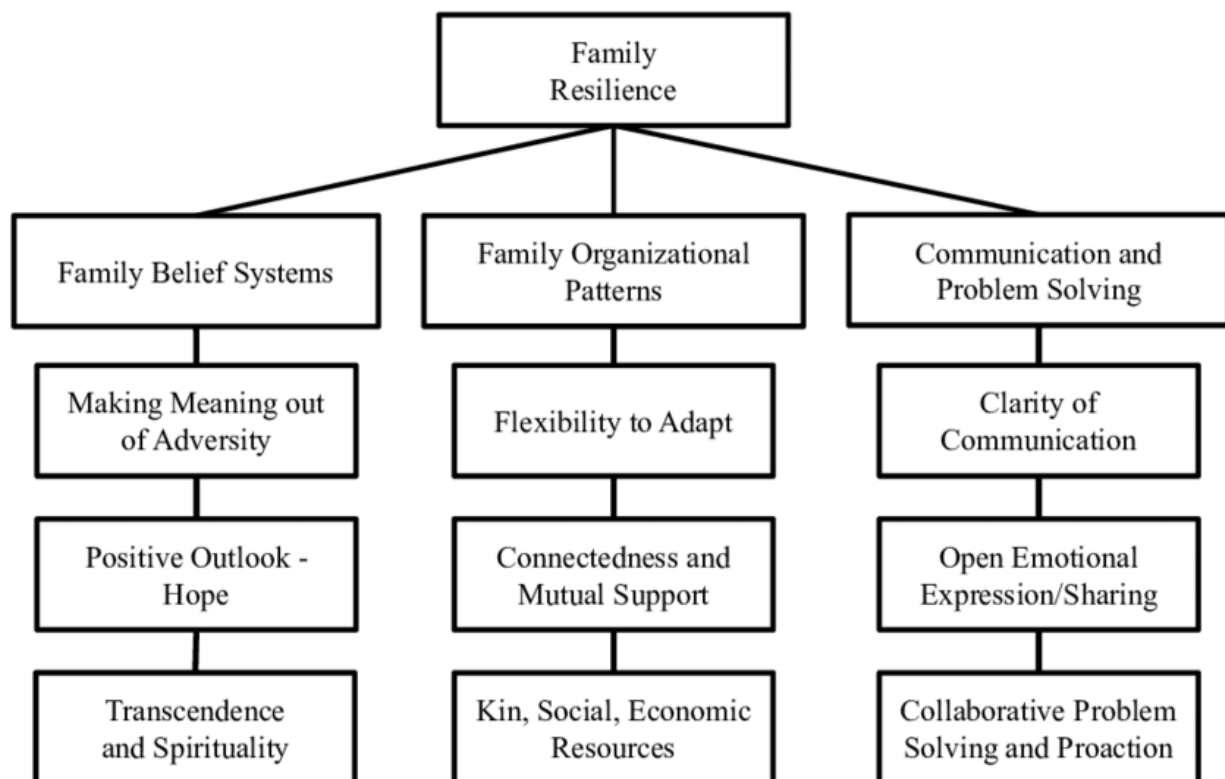


Figure 1: Conceptual Map Showing Walsh’s (Key Processes in) Family Resilience Model (Adopted from Nwanonyiri, Monetti & Boyd-Jackson, 2019, p. 350).

Most of the previous research findings showed that resilient coping is a protective factor for health complaints or for parents of people with ASD (Bekhet, Johnson, & Zauszniewski, 2012). Bayat (2007) surveyed 175 parents of children with autism and asked parents to describe their child, their personal life, and the positive and/or negative effects of autism on their family life. Thematic analysis guided by a family resilience framework (Walsh, 1998, 2003) revealed the majority of the themes showed a positive orientation. There were indicators of resilience as parents' worldviews, values, and priorities demonstrated a sense of hope, meaning, and control. The five themes relating to resilience in the study included the following: 1) pulling resources together and being connected; 2) making meaning out of adversity; 3) changing world view; 4) becoming more compassionate and strength affirming; and 5) having a spiritual belief system. Furthermore, Bayat noted that families' connections improved as they collectively worked to manage the effects of autism in their daily lives.

Research findings presented by Bitsika, Sharpley and Bell (2013) explained that even though resilience could be seen as a potential buffer against anxiety and depression for parents of children with ASD, these findings required further examination before conclusive acceptance. Bitsika and colleagues (2013) proposed that because of the buffering effect noted for resilience, potential avenues for intervention and training for these parents may be considered. For example, psychological resilience is associated with the availability of social supports (Bonanno, Galea, Bucciarelli, & Vlahoz, 2007). Dale, Jahoda and Knott (2006) concluded that the social supports available to the family significantly contributed to the reduction in stress. Social supports that were deemed useful included counseling for parents and their children (Dale et al., 2006). Increasing the availability of social services to parents may lead to increases in parental resilience and, via a flow-on effect, increased ability to cope with the stress of parenting a child with ASD (Bitsika et al., 2013). Parental resilience was found to have a strong positive

correlation to stress in Cripe's (2013) dissertation investigating 206 parents (103 families) with ASD children ages two to 18. In this quantitative study, increased stress was found to be linked to lower family resilience. Cripe concluded that the results demonstrate that families raising children with ASD follow Walsh's (2003) resiliency model; that is, the more the father's and mother's resilience rises, the more resilient the entire family unit becomes.

Resilient parents of a child with autism invariably seek to develop the necessary skills to deal with their child's atypical behaviors. To succeed or to surpass the risk associated with adversity, a person must draw upon all of his or her resources: biological, psychological, social, and environmental assets (Gordon, 1995). Resilience can emerge with support and proper intervention (Sivberg, 2002). Appropriate intervention can help to mitigate the likely feelings of guilt and vulnerability associated with the diagnosis (Stern & Bruschweiler-Stern, 1998). Family members are encouraged and their sense of order or control can be re-established with assistance from the community, extended family, and friends (Naseef, 2006). Generally, in examining human behavior through a multiple systems approach, this theory takes a holistic approach to assessing resilience by considering or emphasizing bio-psychosocial and spiritual functioning as contributing factors to resilience. Therefore, the family resilience theory in this study tries to capture the constructs of stress, coping, and adaptation within the familial (parental) unit while considering the social, relational, and developmental contexts that eventuate within parents during the resilience process (Patterson, 2002). A resilience framework that emphasizes strengths, positive adaptations, and competencies (Luthar & Cicchetti, 2000; Walsh, 2006) is appropriate to comprehend the complexity of coping of parents raising children with ASD and the instrumental processes of adaption to challenging circumstances.

2.12. Theoretical Perspective of the Study

While many theoretical frameworks could have been used to structure the discussions on parenting of a child with autism, for this study, the following section looks at two theoretical frameworks: Family System Theory and Ecological System Theory. Providing a theoretical framework helps to describe and understand a parent's response and also provides further explanations of the challenges, coping mechanisms, and support provisions for parents of autistic children.

2.12.1. The Family System Theory (FST)

The family systems theory maintains that a “family is more than an assemblage of individuals who function in a dynamic interrelationship to each other” (Seligman & Darling, 2007, p. 21), and thus, it is an organized, complex, and interrelated system (Kazak, 1989; Seligman & Darling, 2007). As an assumption of family systems theory, first, *a family is viewed as a whole entity*; it cannot only be understood by looking at its part and second, *a family contains different subsystems*: (a) the partnership subsystem (e.g., interactions between husband and wife or partners), (b) the parent-child subsystem (e.g., interactions between parents and children), (c) the sibling subsystem (e.g., interactions between siblings), and (d) the extended family subsystem (e.g., interaction between the nuclear family members and other relatives) (Meadan et al., 2010).

The parental subsystem is one of the central subsystems. The parental subsystem consists of reciprocal interactions between parents and children regarding discipline, education, and caretaking behaviors (Davis & Carter, 2008; Estes et al., 2013). In addition to caring for their children, parents play different roles: (a) as instructors concerning appropriate cultural norms and

rules; (b) as supervisors guiding social situations and challenges; and (c) as managers regulating their child's life outside of the family unit (cognitively and socially) (Parke, 2004).

Families are often the primary and most powerful system that impacts individual development. All individuals in a family are interactive and interdependent, so anything that occurs to one individual affects all other members in the same family system. The autistic child influences family functioning and interactions between family members, which includes parents, siblings, and the family as a whole. Family systems theory explains a child's ASD as not limited to impacting the child but also as impacting on all the members of the family system. Specifically, the child's disability often interrupts the system's organization, stability, and homeostasis that require a significant change by its members.

For example, compared to parents of typically developing children, parents of children with ASD are more likely to encounter communication challenges and problem behaviors (Davis & Carter, 2008; Estes et al., 2013). Moreover, some parents need to stop working or work fewer hours to fulfill all the caregiving needs, such as accompanying their children to various medical and specialty service appointments. All the changes associated with caring for a child with a disability disrupt the system's homeostasis and thus lead to both long-term and short-term discomfort and distress (Kazak, 1989). This prediction is well-supported by research, which points out that parents of children with ASD are more likely than other parents to experience high levels of parental stress (Estes et al., 2013; Hayes & Watson, 2013).

A child diagnosed with any disability affects the entire family in some way. The disability of the child could lead to marital issues between parents and siblings may feel a sense of resentment (Seligman & Darling, 2007). Though this is not always the case, research by

Urbano and Hodapp (2007) indicated that parents of children with disabilities had a higher divorce rate. The entire family dynamics can be affected as families adjust to the diagnosis and needs of a child with autism (Bilgin & Kucuk, 2010).

A family is an adaptive organization that reconfigures itself to meet changes or challenges (Pinkus, 2006). Each family system responds to the child's disability, adjusts to changes, and finally obtains a new sense of stability, in different ways. These variations are largely determined by the family's adaptability. The ABCX family crisis model summarizes factors that affect a family's adaptability to life events (Hill, 1949; Seligman & Darling, 2007). According to Hill's (1949) ABCX model, the stressor event is (A), the family resources or strengths is (B), and the family's perception of the event is (C), [how they define or attribute meaning to the event]. An event or stressor that cannot immediately be figured out, which will lead the family to a crisis, is the X component of the model (as cited in Smith, Hamon, Ingoldsby & Miller, 2009, p. 96).

The ABCX model states that A (the stressful event) interacts with B (the family's resources) and C (the meaning the family ascribed to the event) to produce X (the crisis). For example, all families of children with ASD experience the diagnostic process (A). However, families have different resources at the time of their child's diagnosis, such as their access to treatments, their ability to afford treatments, the quality of services and support offered by physicians and developmental specialists at diagnosis, and the support parents receive from friends and extended families (B). Additionally, families vary in their perception of ASD and of having a child with a developmental disability (C). All these factors could impact whether families perceive the diagnosis of ASD as a crisis (X) and eventually how they adapt to the child's disability (Seligman & Darling, 2007). Generally, the ABCX model, demonstrated (in

Figure 2), describes a “family transition process” following a stressor event. A period of disequilibrium is followed by three possible outcomes: (1) recovery to the family’s previous level of functioning; (2) mal-adaptation, or permanent deterioration in the family’s functioning; or (3) bon-adaptation, improvement in the family’s functioning over and above the previous level (Hutchison, 1999, p. 417).

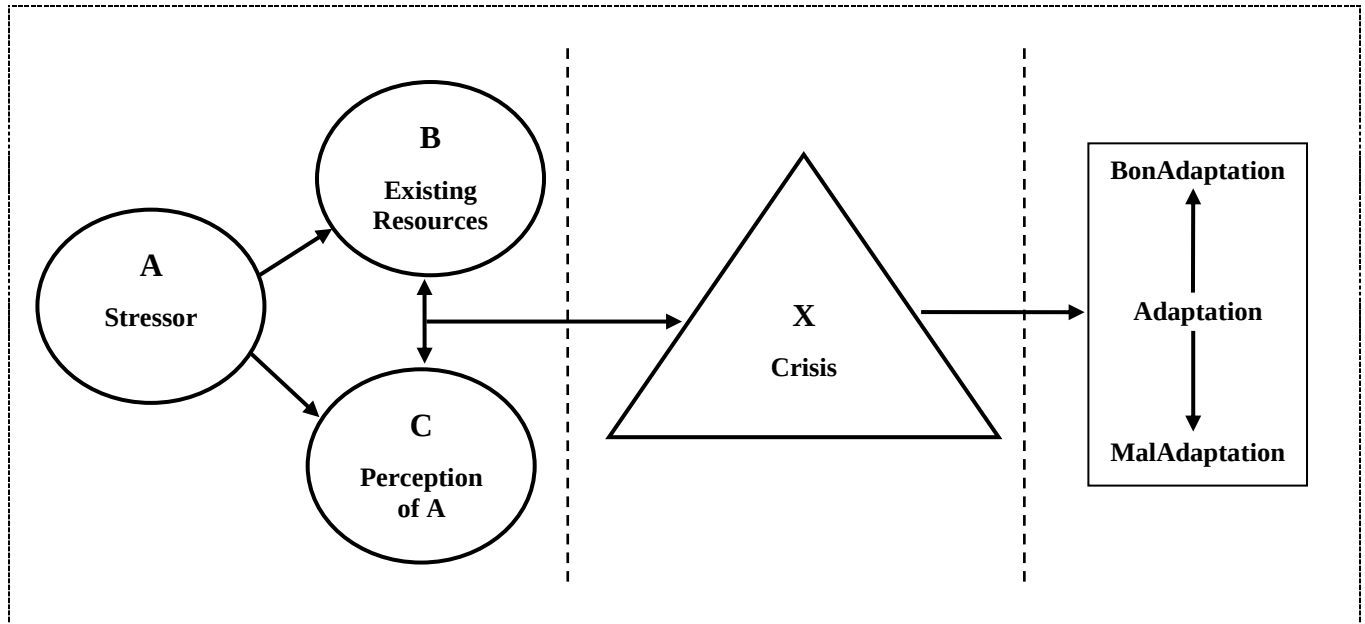


Figure 2: Conceptual Map of Family ABCX Model (Adapted from Lavee, McCubbin, & Patterson, 1985, p. 812).

Hence, members of a family often need to adjust their expectations and goals for the child, adopt new roles, and examine their values and beliefs towards disabilities and ASD. At the same time, they have to cope with their emotions and stigma towards disabilities and ASD within themselves and in the environment and learn new information about the disability and ways to best care for the child. According to family system theory, it is important to examine the larger external systems (including processes and provision of supports by the system) and the mutual interdependence of subsystems in which a family unit functions (Cox & Paley, 2003). For

professionals to understand a child, they must understand the needs and supports for the parents and family as a whole (Turnbull, Turnbull, Erwin, & Soodak, 2006).

Social support is a positive coping strategy that reduces stress in a family system. Support is described as “resources provided by individuals outside the family” and includes informational, instrumental, emotional, and physical/material support (Keller & Honig, 2004, p. 338). According to Hodapp, Fidler, and Smith (1998), several studies have examined the relationship between the size of the family’s social support network and stress in the family. Social supports have been shown to offer relief for families with a child diagnosed with a disability (Boyd, 2002; Dunst et al., 1986b). Although some families display negative coping skills, some report positive coping skills. Positive coping skills may include accepting the child’s disability and feelings towards the child, providing support and much-needed education for the family, ensuring a consistent and active social support system, using community resources, and having faith (Kuster & Merkle, 2004).

This model was chosen since it addresses family stress and the coping mechanisms of families (parents) after a stressful event. In this study, having a child living with autism is a stressful event that challenges the effective functioning of the parent. In addition, the challenges of parents about this stressful event vary from parent to parent based on the level of awareness and available resources. Parents of a child with autism use different coping mechanisms to cope with a challenging situation. As indicated in the model, the parents’ period of disequilibrium may be followed by one of the three possible outcomes: recovery to the parents’ previous level of functioning, mal-adaptation, or bon-adaptation.

Family systems theory shifts the focus from an individual to a family as a system. The family is viewed as a unit; therefore, using the family systems theory, social work professionals can identify family influences on the individual client (Paylo, 2011). Family systems theory is especially important when working with families who are impacted by an ASD diagnosis because the family as a whole is coping with this disorder. The family system impacts a child's development as family members affect the thoughts, feelings, and behaviors of one another (Paylo, 2011). Though autism affects every member of the family, including the child diagnosed with autism, the parents have numerous roles and responsibilities in caring for, guiding, supervising, and overall development of the child. Therefore, based on this model, this study aimed to underscore and address the needs or challenges, coping mechanisms, and supports for parents of a child with ASD. Besides understanding the family dynamics, using ecological systems theory, how environmental institutions in other ecologies affect the wellbeing of parents of a child with autism would also be essential.

2.12.2. Ecological Systems Theory (EST)

The other guiding theory is Ecological Systems Theory (EST). Ecological systems theory in human development can be traced back to Bronfenbrenner's work in the early 1970s, which looks at a child's development within the context of relationships—that form the environment (Bronfenbrenner, 1979). This theory defines complex layers of environment each affecting a child's development and explains the interaction between factors in the child's maturing biology, their immediate family environment, and the societal landscape that directs their development (Fox, 2011).

Thus, Bronfenbrenner's theory of human development has implications for understanding the situation of parents and their children living with autism. Their challenges are affected by the multiple transactional systems in the environment (Cuvo & Vallelunga, 2007). In addition to the direct effects that can occur on a child with autism by interaction with the environment, there are indirect effects. Interactions among the various levels of the ecologies themselves can dynamically and reciprocally transform those ecologies. For example, parents and service providers can affect social policy, which affects the child's immediate environment and the child himself (Cuvo & Vallelunga, 2007).

When considering the lives of children with autism and services for them several levels of the environmental ecology interact with each other including family members, various service providers, the immediate community, the larger society, and culture. These ecologies provide the context that can be either facilitative or non-facilitative to the development of the autistic child as the child interacts with these environments and is changed by them; changes in the child can also produce changes in the various levels of the social ecology (Cuvo & Vallelunga, 2007). For instance, the behavior of the child will affect the behavior of parents, friends, childcare staff, and their behaviors will also affect the child. Thus, a child with autism displaying disruptive or aggressive behavior is more likely to elicit restricting/punishing parenting behavior, while a friendly and attentive child is more likely to evoke positive reactions from the environment (Sameroff & Fiese, 2000).

The ecological model of human development proposed four layers (mutually connected structures) of influence that affect a child's development: microsystem, mesosystem, exosystem, and macrosystem. Each system contains roles, norms, and rules that shape an individual's development (Fox, 2011).

The microsystem, the most basic ecological level, is the immediate temporal setting in which the child interacts with the environment. It consists of people and activities in an individual's immediate surroundings such as families, peers, and teachers (Grace, Hodge, & McMahon, 2013). A child with autism operates in various microsystem structures and processes at home, at school, and in the community (Cuvo & Vallelunga, 2007). According to this theory, if the relationships in the microsystem fail, the child with ASD will not have the tools to explore other parts of his/her environment, thus impacting his/her development and causing more deficiencies (Fox, 2011). This theory further postulates that children with autism are dependent upon their microsystem environment beginning with the family, then extended family, school, church, and other community agencies that provide support and treatment (Webb, 2012). Factors at a microsystem level can directly affect care and support for children with disabilities; therefore, practitioners need to assess parenting practices and parent-child relations (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010).

Churchill et al. (2010) further argue that caregivers of children with special needs are at increased risk of stress, depression, negative emotional state, and marital conflicts which could undermine parenting practices and parent-child relations. Counseling and intervention strategies that reinforce appropriate coping strategies and self-reliance can foster a sense of empowerment, potentially leading to better parenting skills.

The second layer of the ecological model, mesosystem, consists of the connections between microsystems. The mesosystem can include networks of interactions between an individual's family and school, an individual's family and church, or between the individual's family and neighbors. For example, parents and teachers of a child with ASD can collaborate to promote the child's language development. This means the relationships between two settings, such as the parent-health professional relationship, the parent-educational professional relationship, or the relationship between the parents (Fox, 2011). The degree to which those

relationships are healthy or unhealthy can influence the child positively or negatively. At the mezzo level where children with developmental disorders and their families interact with institutions such as schools and social service agencies, transpersonal factors (such as family and organizational dynamics) can influence the child's quality of life (Ferguson, 2001).

Thus, understanding the factor associated with the caregiving of children with special needs necessitates an examination of the interactions at the mesosystem levels, as a mesosystem comprise the interactions or interrelations among two or more micro-systems. That is, experiences involving one micro-system (e.g., caregivers' marital relationship, religious and social support) may influence another micro-system (e.g., caregiver-child relations) each of which can affect the child with the developmental disability (Algood, Harris & Hong, 2013). Religion as a source of social support is another mesosystem used by caregivers of children with disabilities that are related to positive outcomes and can influence the quality of parent and child relations (Algood et al., 2013).

Exosystem is the third level of the ecosystem that has an indirect influence on the child with autism via their direct impact on other persons, who in turn interact with the child (e.g., linkages and processes among various contexts in which parents and service providers may interact without the child) (Cuvo & Vallelunga, 2007). Examples of the exosystem include an individual's neighborhood, the workplace, government agencies, the economy, and communication systems (Bronfenbrenner, 1979). For instance, the decision of a state government to cut off funding for special education programs in schools can impact the development and functioning of individuals in need of such programs in that state. On the other hand, according to Petra (2012), other more distant relations that affect the child with autism and the parent indirectly are found in the exosystem, which includes not only larger social institutions such as community support and health services, but also other structures such as the world of work and mass media that operates in the ecosystem.

Finally, the outermost layer, macrosystem, the ‘societal blueprint’ (Bronfenbrenner, 1986), is the super-ordinate environmental level that subsumes the other ecological levels affecting human development at the societal, ideological, and cultural levels (Lerner, 2005), as depicted in (Figure 3, on page 99). Societal regulation and cultural values affect children with autism via state and federal legislation, judicial opinions, governmental administrative regulations, health insurance practices, and other societal behavior directed toward them (Cuvo & Vallelunga, 2007). For instance, parents’ allowance may enable parents to stay at home with the child on the spectrum during infancy, and later access to childcare outside the home may promote the child’s social and language development and allow parents to seek employment (Petra, 2012). Another example could be that culturally held beliefs of disability and children can affect the family’s perception of how to adapt to and use social support. Therefore, intervention programs should pay particular attention to the culture and lifestyles of families raising children with special needs at the macrosystem level and enhance the parenting quality of low-income, racial and ethnic minority caregivers who are often overburdened and feel helpless because the intervention programs and strategies may not be consonant with their culture (Algood et al., 2013).

Ecological systems theory and its conceptual fit with the “person-in-environment” perspective (Hepworth, Rooney & Larsen, 2002) is an important tool that enables social workers to look beyond the individual and the family. As a holistic approach that looks at the client and his/her environment, ecological systems theory provides social workers with the possibility for intervention “at any point along a continuum” from micro through mezzo to macro levels (Walton, Sandau-Beckler & Mannes, 2001). From an ecological perspective, social workers should focus on both the person and situation or environment (Compton, Conway, Stinson, Colliver & Grant, 2005), and the choice of practice framework should depend on the kind of problem and the situation of the client.

According to Pardeck (2015), the ecological approach provides strategies that allow the social worker to move from a micro-level of intervention to a macro level of social treatment as this perspective not only helps the social worker influence a client system through policy and planning activities but also psychotherapy and other micro-level approaches.

Generally, factors affecting parenting practices for children with disabilities are complex and multi-faceted, which provides a rationale for ecological-based practice implications to provide appropriate intervention at micro, meso and macro levels (Algood et al., 2013). Hence, parents and service providers should work collaboratively in their microsystems to form a contented mesosystem, by consistently implementing services. Service providers should address the many family needs by working collaboratively toward affecting societal behavior and public policy (at the macrosystem). For example, parents, professionals, and service organizations could collaborate to exert contingencies on state legislators to appropriate funds to create professional training programs related to autism (Cuvo & Vallelunga, 2007).

Pardeck (2015) stated that the ecological perspective makes a significant departure from the traditional methods of casework, group work, and community practice. Social workers can conceptualize the problems confronting their clients in such a way that effective treatment involves not only working with the client but also with the systems that facilitate social functioning including the client's family, neighborhood, community, and other critical social systems.

To sum up, from this research point of view, applying genetic theory, theories of mind and mind-blindness, family resiliency, and stress and coping theory described above with parents of a child with autism contribute important knowledge to understand and explain the challenges, coping mechanisms, and available support systems. Both family systems theory and Bronfenbrenner's ecological systems theory help us to understand the dynamics of interactions

between parents and their child with autism as well as how the support/resources in the environment affect them. In complementing each other and forming a strong foundation for the present study, both family systems and ecological theorists view family members as having a mutual impact on each other; therefore, parents are affected by their children's ASD and parents' well-being could also affect their children's well-being and development. Furthermore, from the ecological systems theory point of view, parents' ability to cope with the challenges could also be affected by multiple cultural and social systems or resources in the ecology.

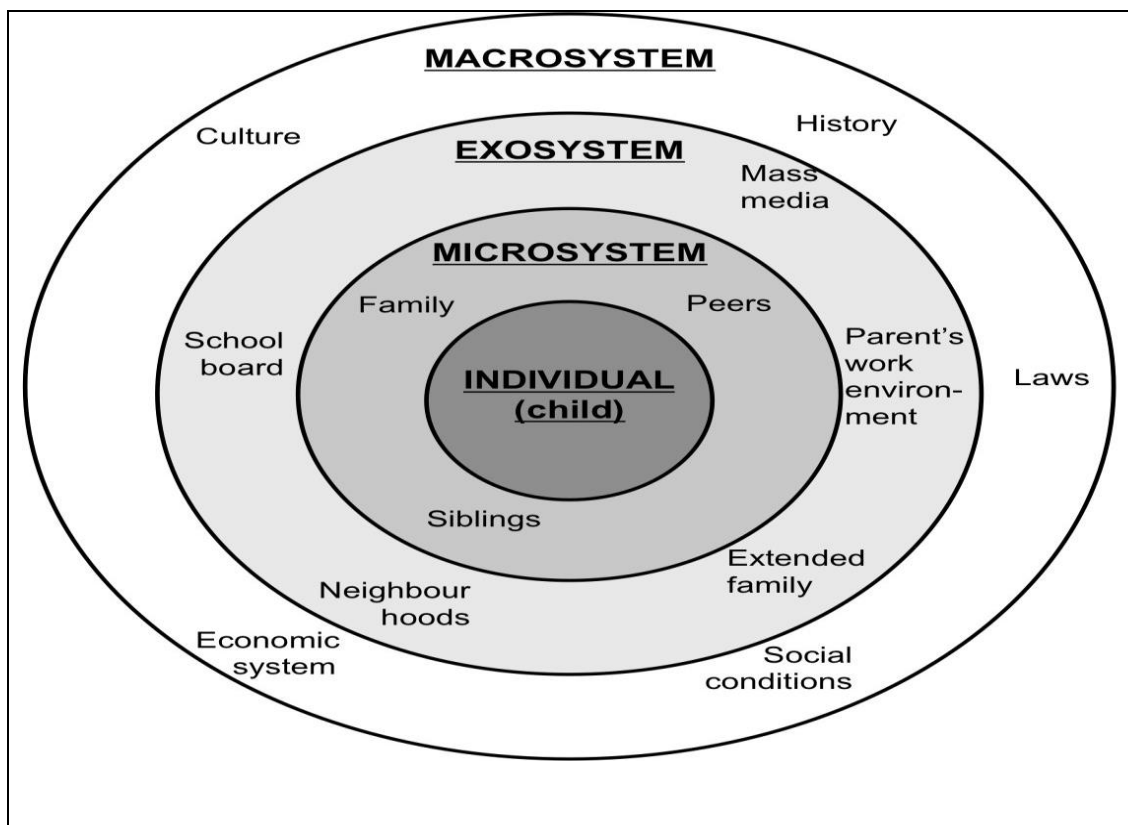


Figure 3: Conceptual Map of Bronfenbrenner's Ecological Systems Model displaying the multiple contextual levels (Adapted from Niederer et al., 2009, p. 3).

2.13. Conceptual Framework

A “conceptual framework is described as a set of broad ideas and principles taken from relevant fields of inquiry and used to structure a subsequent presentation” (Abiy et al., 2009, as cited in Creswell, 2009, p. 8). The conceptual framework shows how a concept is related to another concept. Figure 4 presents a diagrammatical representation of the conceptual framework of the study.

In this conceptual framework, the unidirectional boldfaced arrow implies how the existence of a child with autism can produce a challenge on the parents, and as a result, the parents may employ different coping mechanisms and available support systems to cope with the challenge. The use of available support systems may also buffer the challenges and improve the coping mechanisms of the parents. Besides, the tinny single directional arrows that connect the circle with the components in the box illustrate the items to be measured by the instruments/tools in this study.

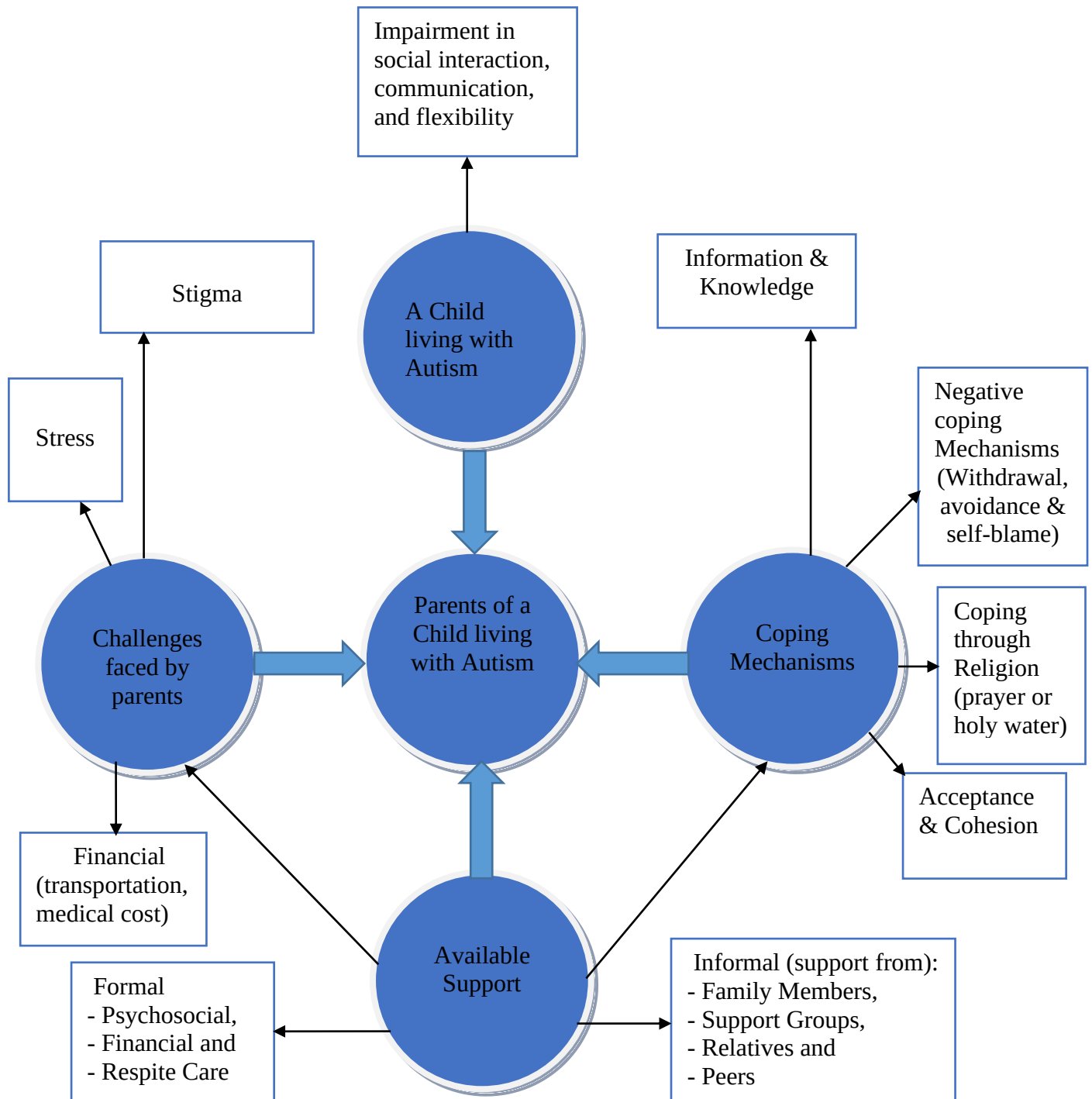


Figure 4: Conceptual Framework of the Study

2.14. Literature Search Strategy

Exhaustive literature searches were conducted electronically in multiple online databases of (PsycNET, ProQuest, PubMed, EMBASE, CINAHL, Educational Resource Information Centre (ERIC), SciDIRECT, SAGE, Academic Search Primer, Web of Science, and Google Scholar), reference lists from key articles and ancestral (a manual) search of the Journal of Autism & Developmental Disabilities, Journal of Autism, and Journal of Intellectual & Developmental Disabilities). Terms used in the searches included autism, autism spectrum disorder, autism awareness, autism and challenges of parents, parental stress, stigma, financial/economic challenges, coping mechanisms, supports and autism, interventions, parenting, family life, children with autism, siblings of children with autism, Ethiopia and autism, autism in Ethiopia, and autism in Africa. These keywords were used singularly or in pair-off to form key phrases. Criteria for inclusion (selection) in this study consisted of studies (a) providing clear/sufficient information on the (context, theory, method, and outcome); and (b) published articles in peer-reviewed journals in the English language were used as a qualifier to support the investigation of the topic. The accessed literature was compiled in a folder organized by the major themes of the study (See Appendix-I, a snapshot of how themes were organized in the literature review).

2.15. Summary and Implications of the Literature Review

The review of literature in this chapter begins with the history, nature, definition, etiology, and prevalence of ASD to provide information on the general characteristics of autism spectrum disorders and to lay a foundation for understanding the challenges, coping mechanisms, and available supports for parents of a child with autism. The task was daunting due to the lack of adequate literature on ASD in Ethiopia.

Autism spectrum disorder (ASD) is differentiated from other developmental disorders by significant impairments in social interaction and communication, along with restrictive, repetitive, and stereotypical behaviors and activities (American Psychiatric Association, 2013). Individuals diagnosed with Autism spectrum disorder (ASD), currently estimated to occur one in every 59 births in the USA (Baio et al., 2018; Christensen et al., 2016), exhibit varying degrees of intellectual ability and social impediment. Generally, children with ASD have lifelong challenges on how to be a social being, to take care of themselves, and to actively participate in the community.

ASD is a multifactorial condition potentially caused by genetic and non-genetic [environmental] factors (Rutter, 2005). Epidemiological findings have helped to include and exclude various significant factors. Most importantly, however, it is now beyond debate that autism is not caused by poor parenting or an unemotional ‘refrigerator mother’, as previously suggested by Bettelheim (1967). Though the exact causes for ASD remain unclear, the symptoms of ASD, including problems with social relatedness, communication and restricted interests, and repetitive behaviors are now much better understood than they had been in the past.

The literature stated parents can face many challenges, affecting not only the child with ASD but also family functioning and their quality of life. Difficulties can arise across a range of areas, including behavior, communication, sleep, personal care, and independent living skills (Matson, Mahan, & Matson, 2009). Lyons et al. (2010) have shown that the severity of ASD symptoms is the strongest and most consistent predictor of parental stress. It seems that the more severe a child’s ASD symptoms, the greater the degree of parental distress (Hastings & Johnson, 2001). Therefore, some parents isolate themselves and their families from social contact with the outside world altogether or restrict their social life to immediate family members, a few friends, and other parents of children with ASD (Gray, 1994; Rodrigue et al., 1990). Parents generally are concerned for the well-being of their other children and commonly cite the loss of typical

family socializing experiences as one of the worst effects of autism on their families (Gray, 1994). As symptoms of autism increase in severity, there is a corresponding effect on parental psychosocial well-being (Lyons et al., 2010). Some scholars are involved in a heated debate about whether the high parental stress levels are due to the primary symptoms of autism or the behavioral problems associated with the disorder. To buffer the stress, parents may cope through formal and/or informal support systems.

The theoretical framework presented in this literature review has a guiding role in this research. For example, genetic theory and theory of mind and mind-blindness have endeavored to describe the cause and the characteristics of autism, respectively. Family resilience and stress and coping theory enlighten parents' pliability in the presence of challenges. On the other hand, family systems and ecological systems theories explain how interactions in the family and with ecology affect children and parents of a child with autism. In addition, these theories explain how resources/supports in the ecology and family buffers the challenges faced by parents.

This review of the literature also revealed a very limited number of studies exploring the challenges, coping mechanisms, and support provisions for parents of a child with autism in Addis Ababa, and Ethiopia in general. Some of the studies focus on intervention (autism care and treatment), and attitudes of general education teachers toward inclusion of children with ASD. Therefore, little is known about the challenges, coping mechanisms, and services for parents of children with ASD in Ethiopia. Clearly, there is a gap in the literature on parenting a child with autism. There is a need for more research on parenting to provide a richer understanding of the challenges and coping mechanisms in Ethiopia. In addition, supports for parents of children with ASD, how key stakeholders view the efficacy of various interventions, barriers, and challenges they face in implementing programs and practices, and how they view their relationships with one another to meet the needs of these parents and children need to be researched both at Addis Ababa city and country-level as well.

CHAPTER THREE

3. Methods

“Whoever is searching for the human being must first find the lantern” Nietzsche

(cited in Manen, 1990, p.4).

3.1. Introduction

The methodology is the theory and justification for the methods of a research project (Carter & Little, 2007), while the method refers to how data and analysis are produced in research. This chapter describes and discusses the overall method and research design used in this dissertation. This includes the choice of research method, the context in which the research is carried out, and the epistemological underpinning of the overall study. Thus, this chapter briefly outlines the research philosophy, design, study area, population and sample, eligibility criteria, sampling technique, instruments of data collection as well as the process followed to conduct the study. The method of analysis and ethical considerations used in the study are also described.

3.2. Philosophical Stance

Philosophy is concerned with views about how the world works, and as an academic subject, focuses primarily on reality, knowledge, and existence. Research philosophy is also called a research paradigm, which refers to the “underlying intentions or reasons for conducting the research process including the basic values and beliefs about research” (Dudley, 2005, p. 21).

The paradigm gives direction and justification to researchers' actions (Creswell, 2009) or rules for conducting research which can be characterized through ontology¹ and epistemology². Thus, for the researcher of this study, a research philosophy is a belief about the way (how) data should be gathered, analyzed, and used.

Writers categorize paradigms into different categories. For instance, Robson (2002) presents post-positivism, constructivism, critical or emancipatory, and pragmatism. Likewise, Creswell (2009) provides the four research paradigms ('worldviews'): post-positivism, constructionist, advocacy, and pragmatism. The philosophical foundation for this study is based on a pragmatist philosophical worldview. Pragmatism is a recent paradigm compared to others. According to Creswell and Clark (2011), mixed methods research as a methodology follows a pragmatic paradigm, which serves to give direction for the data collection and analysis as well as the mixing of qualitative and quantitative approaches in different phases of a study.

Advocates of mixed methods research identify themselves with the pragmatic paradigm and they draw a strong association between mixed methodology and pragmatism (Tashakkori & Teddlie, 2003). Johnson and Onwuegbuzie (2004, p. 17) argued that pragmatism takes the "middle position philosophically and methodologically," and in that, it offers a method for selecting methodological mixes that can help researchers better understand and be able to answer their research questions.

¹ *Ontology is the study of [existence and] the nature of reality* (Creswell, 2010) or the philosophy of what we believe to exist (philosophy of being) (Smith, 1998).

² *Epistemology is the theory of knowledge [ways of knowing] and the notion of how the researcher "knows what he or she knows"* (Creswell, 2010, p.17) or it explains how we know what we believe to exist (philosophy of knowledge) (Smith, 1998). At the ontological level, the researcher should define the concepts and reality of the investigated phenomena (Polit and Beck, 2004), and simultaneously, at the epistemological level, the researcher should clearly state the way (processes) of creating, acquiring, and communicating knowledge and reality of the investigated problem (Scotland, 2012).

According to pragmatists, what is right is what functions (Poller, 2006, cited in Genene 2015). In pragmatism, “there is a concern with the application—what works and solutions to problems” (Patton, 2002, cited in Creswell, 2009, p. 10). Creswell (2003) argues pragmatists link the choice of approach and methods directly to the purpose and nature of the research questions. Once again, Creswell (2009) contends that central to the pragmatic perspective is the problem rather than the research approach. Similarly, Tashakkori and Teddlie (2003) stated that pragmatism gives primary importance to the research question rather than to the approach or philosophical worldview that underlies the method. It focuses on the research problem and the use of pluralistic approaches to derive knowledge about the problem. Ontologically, in pragmatism social reality has both objective and subjective dimensions; epistemologically, it is the mixture of positivist and interpretive science to provide both the breadth and depth of meaning. Thus, from the methodological viewpoint, mixed-method (both qualitative and quantitative) analysis, through cases and variables is used (Creswell, 2009).

Pragmatism allows flexibility in the research process. Pragmatism is not committed to any one system of philosophy and reality. Accordingly, it allows the flexibility of reasoning that moves back and forth between induction and deduction (“abductive” reasoning) (Morgan, 2007). In other words, it allows the use of different techniques in a holistic approach to achieving the research objectives. Researchers focus on the research problem and apply all available approaches to understand the problem instead of focusing on a paradigm. Individual researchers are free to choose the design, method, and procedures of research that best meet their needs and purposes (Creswell, 2009). Using the pragmatist philosophical worldview, this study sought to examine the challenges, coping mechanisms, and available support for parents of a child living with autism in Addis Ababa.

3.3. Research Design

Research design is a “plan or a proposal to conduct research, involving the intersection of philosophy, strategies of inquiry and specific methods” (Creswell, 2009, p. 5). The design of the study was a cross-sectional, sequential mixed method. Cross-sectional research is research conducted at a single point in time (Kreuger & Neuman, 2006, p. 31). This research is a cross-sectional study conducted at one point in time as a requirement for doctoral education in Social Work and Social Development. In a mixed-method design, the strength of both quantitative and qualitative approaches can provide the best understanding (Creswell, 2009). Thus, social work research can require both qualitative and quantitative methods, and researchers can use them in complementary ways (Kreuger & Neuman, 2006).

A research design serves as a plan that guides the researcher to connect the empirical data to the study’s research questions, and ultimately, to answer the research questions that were set to guide the study (Yin, 2014). Mixed research methodologists (Creswell & Clark, 2011; Tashakkori & Teddlie, 2003) have developed several mixed-method design types. Of this, Creswell and Clark (2011) identified a sequential design as beginning with either a quantitative or qualitative methods phase and then using the resulting data to inform the second phase.

Exploratory sequential design starts with the collection and analysis of qualitative data followed by the collection and analysis of quantitative data. It is conducted in two phases. The first phase involves qualitative data collection, and the second phase involves quantitative data collection. The purpose of exploratory sequential research design is to use the findings of the qualitative study to identify the most important variables, to provide deep and rich descriptions for the quantitative data, and/or to generalize the findings of the study (Teddlie & Tashakkori, 2009).

Rational for Exploratory Sequential Mixed Method: Regarding the types of mixed methods design, Creswell (2009, p. 209-210; 2012, p. 540) elaborated that there are “six mixed methods research design commonly used in social science and educational research: the explanatory sequential design, the exploratory sequential design, the sequential transformative design, the concurrent triangulation design, the concurrent embedded design, and the concurrent transformative design.” All six types of MMR design suggested by Creswell may largely fall into two broad categories: sequential and concurrent designs—the first being two-phased and the latter single-phase study. The explanatory sequential design is a two-phased model which uses qualitative results to supplement the findings of a primarily quantitative inquiry and vice versa for exploratory sequential design (where quantitative data are collected to supplement a prior qualitative finding). The sequential transformative design is also a two-phased project with an initial phase (quantitative or qualitative) followed by a second phase (quantitative or qualitative) that builds further on the earlier phase.

On the other hand, concurrent triangulation design involves collecting both quantitative and qualitative data simultaneously and then comparing them for convergence or divergence and thus enables cross-validation or confirmation. The concurrent embedded design is a single-phase model which involves simultaneously collecting both quantitative and qualitative data with one guiding the project and the other intended to support it. Finally, the concurrent transformative design involves collecting both quantitative and qualitative data with a strong theoretical perspective and shares the design features of either an embedded or triangulation approach.

In this research project, among the six MMR designs suggested by Creswell, the exploratory sequential design was selected because “it enables the researcher to identify attributes or variables—actually grounded in the data obtained from study participants” (Creswell, 2012, p. 544). Creswell further insisted that the exploratory sequential design has been found preferable to other MMR designs when the researcher aspires to look for the most important attributes or variables for the quantitative part of the study. As such, the application of the exploratory sequential design for this research project would enable the researcher to derive sets of attributes symbolizing challenges, coping mechanisms, and supports for parents of children with autism.

This study employed a sequential exploratory design, taking the two autism centers as a study site. The exploratory sequential design enabled the investigator to obtain themes and the most important variables constituting the challenges and coping mechanisms. This type of research design is chosen when the most important variables are not known, to identify the most important variables for the quantitative study (Creswell, 2009). The reason for the selection of this design type was, therefore, (1) to use the qualitative data to identify variables that constitute the challenges and coping mechanisms of the parents, and (2) to use the quantitative data to determine the levels of the challenges, the most used coping mechanisms, and the relationships between the identified variables (stress, stigma, and financial constraints) and coping mechanisms. Thus, an explanatory sequential mixed research approach was considered as a pertinent approach to address the objective of the research. In addition, this approach ensures the validity of the overall research and provides the benefits of triangulation and complementarities.

This research is a descriptive study. The purpose of descriptive research is to provide a detailed picture of a specific situation, social setting, or relationship (Kreuger & Neuman, 2006). Similarly, to examine the problem, the study employed an exploratory sequential mixed method design. According to Creswell (2007), a mixed-method design is useful to capture the best of both quantitative and qualitative approaches and to develop a detailed view of the phenomenon. Hence, the qualitative data were analyzed using thematic data analysis and the quantitative data were analyzed using descriptive and inferential statistics. The exploratory sequential mixed-method strategy used in this study is indicated in the following visual model (Figure 5).

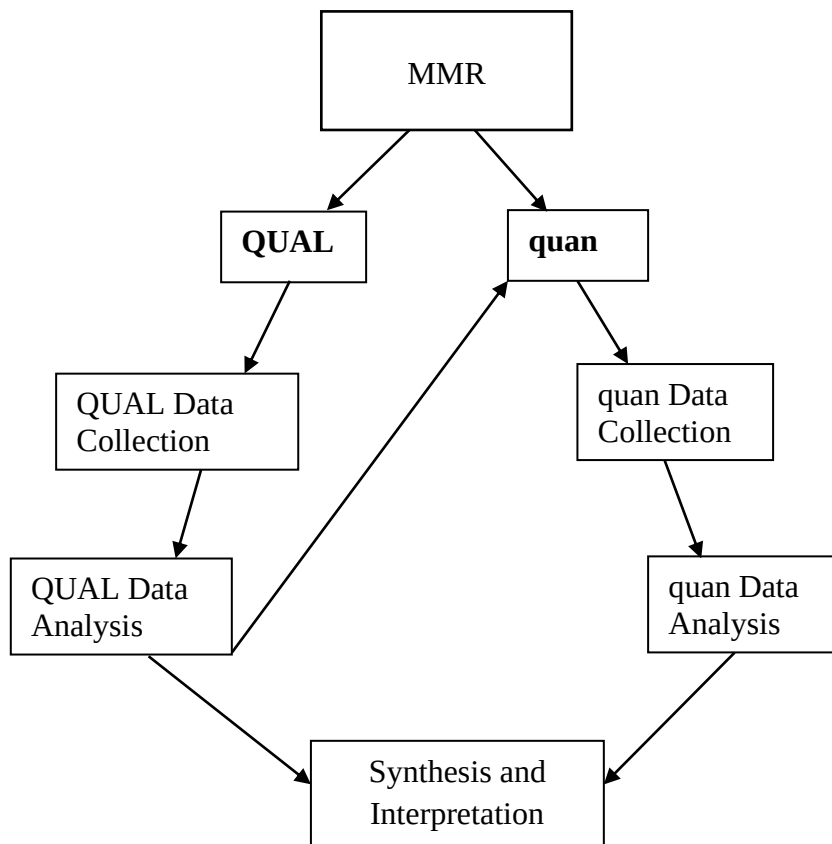


Figure 5: Shows a conceptual map of Exploratory Sequential Mixed Method (Adapted from Creswell, 2003, p.213).

3.3.1. The Rationale for Mixed Methods Research (MMR)

MMR can be defined as “an approach to research in the social, behavioral, and health sciences in which the investigator gathers both quantitative and qualitative data, and then draws interpretations based on the combined strengths of both sets of data to understand research problems” (Creswell, 2014, p. 2). MMR is narrowly defined as “empirical research that involves the collection and analysis of both qualitative and quantitative data” (Punch, 2009, p. 288). Combining both qualitative and quantitative data, adopting mixed-method research provided the best understanding of a research problem because it opens the door to multiple methods of data collection and analysis (Creswell, 2003).

There are several advantages of employing multi-methods in a single study. Firstly, different methods can be used for different purposes. Secondly, the approach allows triangulation. Triangulation helps to ensure the credibility and validity of a research process and results (Johnson, Onwuegbuzie, & Turner, 2007). Thirdly, it helps to explain qualitative results with subsequent quantitative data, and lastly, the multi-method approach enhances a study with a supplemental data set, either quantitative or qualitative (Migiro & Magangi, 2011). According to Creswell (2009), in mixed research, the researcher converges or merges qualitative and quantitative data to provide a comprehensive analysis of the research problem.

Of course, the abovementioned way of doing research is not only possible but also desirable. It could be argued that the use of multiple methods and techniques is one of the best ways to improve the quality of research (Mouton, 1996); to offset the weaknesses inherent within one approach/method with the strengths of the other (Creswell, 2003), and to enhance, elaborate, or complement data from the other source (Creswell, 2012). Therefore, integrating both

approaches has a greater likelihood of enhancing the research findings and offers a greater understanding of the topic (Masadeh, 2012). To use the benefits of each method, we employed a sequential exploratory design to integrate qualitative and quantitative methods (Creswell & Clark, 2017).

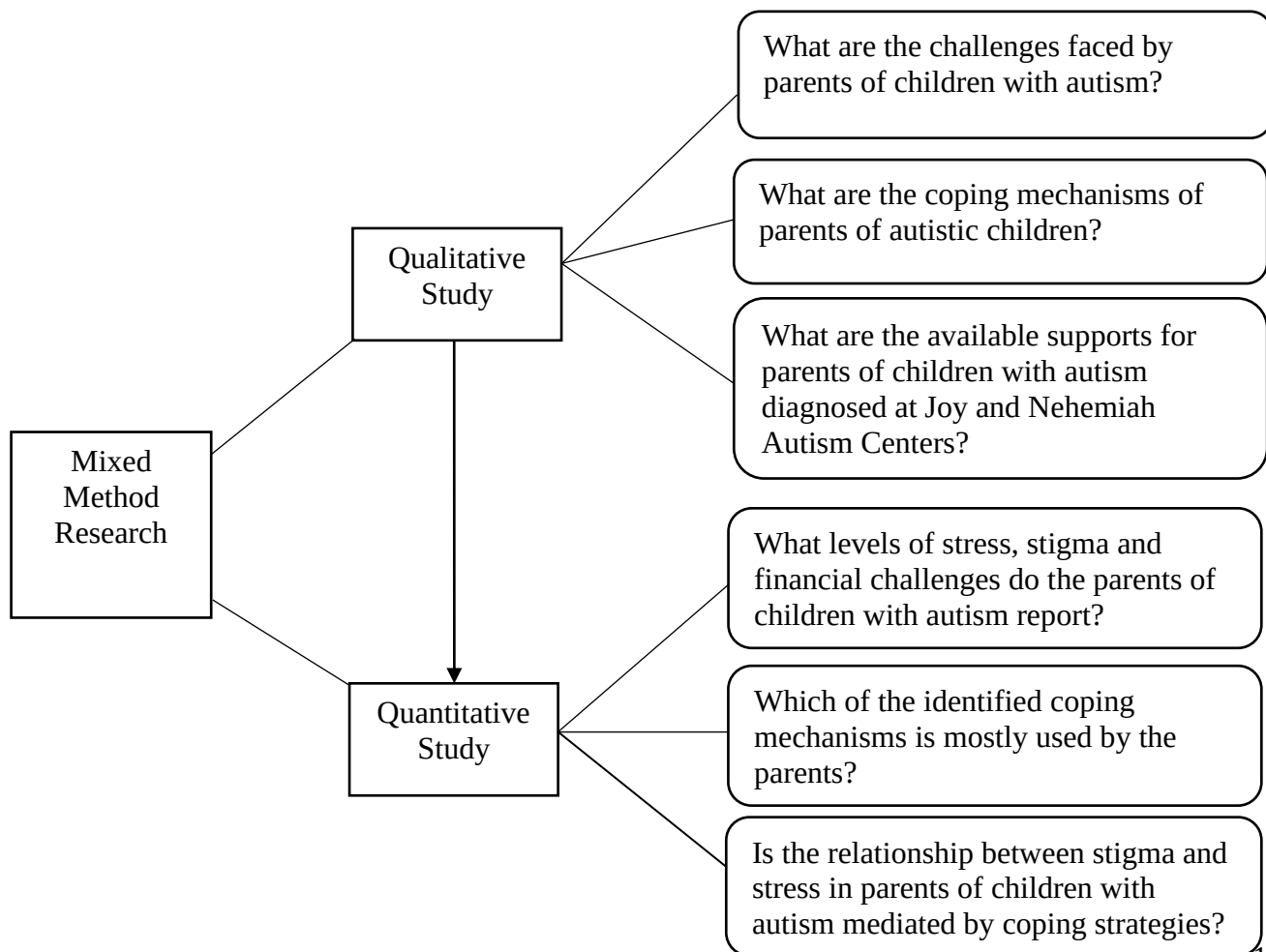
The data collection procedures involved two phases as per sequential exploratory techniques (Creswell, 2012). An exploratory sequential mixed method design is an approach that involves the first phase of qualitative data collection and analysis followed by the second phase of quantitative data collection and analysis that builds on the results of the first qualitative phase (Creswell, 2014). Sequential exploratory research design mainly gives priority to qualitative data and supports the qualitative results via quantitative (Creswell, 2012). Therefore, the application of exploratory sequential design enables the research to produce more detailed and, more or less, generalizable results by further building on and refining the initial findings of the qualitative exploration (Creswell, 2008). In this regard, Creswell (2012) stated, *“The purpose of an exploratory sequential mixed methods design involves the procedure of first gathering qualitative data to explore a phenomenon, identify themes (the most important variables), and then collecting quantitative data to explain relationships found in the qualitative data”* (p.543).

Mixed methods research offers a practical approach to addressing research problems and questions ... because these problems and questions are examined in different ways (Graff, 2013). One of the most prominent scholars on this topic is Creswell (2014, p. 3) who argues the application and selection of a mixed-method approach “should depend on the nature of the research questions.” Flyvbjerg (2011) contends that good research makes use of the methodology which best answers the research question at hand. Thus, the rationale for using a mixed-methods

approach in this study was the presence of two types of research questions that entailed a pluralistic approach to address them.

The first, third, and sixth research questions (see page 10) are qualitative and require the use of a qualitative method. The second, fourth, and fifth research questions (see page 10) are quantitative research questions that require the use of quantitative methods (as shown in figure 6). Neither the qualitative nor the quantitative method separately can address the research questions raised in this study. By combining both qualitative and quantitative methodology, the investigators were able to build on the strengths and make up for the weaknesses in the other to address those [six] research questions (Creswell & Clark, 2011).

Figure 6: Shows a schematic representation of the research method based on the research questions



3.4. Study Area

The study was conducted in Addis Ababa. Addis Ababa is the capital city of Ethiopia with a population of 3,384,569 and an area of 530.14 square kilometers according to the 2007 population census. Addis Ababa has ten sub-cities at which the city lies at an altitude of 7,546 feet (2,300 meters) and is a grassland biome, located at 901°48'N 38044°24'E 9.030N 38.740E (CSA, 2007). This study was conducted in two organizations located in Addis Ababa, Ethiopia. The two organizations are namely the Joy Center and the Nehemiah Autism Center.

3.4.1. Backgrounds of the Organizations

Joy Center has a compound located in a peaceful neighborhood in Addis Ababa. The Joy Center for autistic children is found at 'Kirkos' sub-city, opposite the Vatican Embassy. Nia Foundation established the center and the name Joy is derived from '*Jojo*'-meaning of joyful place. Nia Foundation is a native, non-political, non-religious, and non-profit-making foundation established in 2002 G.C., by Zemi Yenus, a mother of an autistic son (Nia Foundation, 2012). The center is now serving 80 children and 400 children are on a waiting list (Minasie, 2017). The compound consists of the playground area and therapy rooms, where various forms of therapies are provided for children with autism. The staff is highly dedicated to training the children to be capable of daily life skills such as toilet training, communication, and self-feeding. In addition to the treatment and education for children, the foundation also offers counseling and training support for parents. The foundation encourages parents to be active participants in the development of their children. It works closely with parents, extended family networks, and children as well as the community with the goal of integrating children with autism into society.

The second organization where this study was conducted is the Nehemiah Autism Center, an indigenous, non-governmental, and non-profit organization operating since 2011 G.C. Nehemiah Autism Center is located in Bole Sub City around a place locally known as 'Megnagna'. It was established by a mother of an autistic child who was tired of the long waiting list at the only center providing service for such children in the country at the time. The center was commenced by providing service for only two children. Currently, 60 children are receiving a school-based intervention, and 400 children are on the waiting list (Minasie, 2017).

The organization mainly focuses on providing training and treatment to children with autism. It also provides counseling and support to parents interested in the education and development of their children. Furthermore, the organization is involved in awareness-raising programs for society. The organization mainly assists parents that lack the financial capacity to cover the treatment of their child with autism by offering free treatment to their children. The compound is located in a refreshing environment and consists of a playground for the children.

The two centers were purposely selected as a study area for a couple of reasons. Firstly, these are the only centers providing support for autistic children and their parents in Addis Ababa and Ethiopia. Secondly, there is no organized database about the location and number of autistic children and their parents in the city. Thirdly, the centers are providing integrated services for both children with autism and their parents. Therefore, conducting research in these settings to examine the challenges, coping mechanisms, and supports provided for parents is both logical and reasonable.

3.5. Sources of Data

In this study, both primary and secondary data sources were used. The primary data are those collected for the first time and thus happen to be original in character, while the secondary data, on the other hand, are those which have already been collected by someone else (Kothari, 2004). A mixed-method was employed to collect relevant primary data on the socio-demographic characteristics, challenges, coping mechanisms, and available support systems. To attain this objective, the major sources of data were (A) Parents of children with autism obtaining service from the centers; (B) Founders of the institution (they provided information especially concerning the existing support system and intervention practice in the centers for parents of children with autism); and (C) The centers' (school) teachers and medical professionals. It was believed that they have considerable interaction with parents of children with autism and hence, they would provide information on the parents' situations.

Secondary sources were utilized to obtain information on the total number/list of parents/who are obtaining service from the centers, and the total number of children attending education and treatment. A list of professionals and requirements of parents to receive service from the centers was reviewed through official reports and documents of the centers. In addition, materials like books, journal articles, studies, electronic copies, magazines, and various national and international reports were also used to provide detailed information and to boost the research findings.

3.6. Unit of Analysis

A unit of analysis is the “case.” A case could be an individual [for instance, the classical case studies usually focus on individual person as a case] or of course, the case can also be some event or entity other than a single individual like small groups, communities, decisions, programs, organizational change, and specific events (Yin, 2014). Taking this into account, the unit of analysis for this study was the parents of children with autism receiving services at Joy and Nehemiah Autism Centers. Since the objective of the study was to assess the challenges, coping mechanisms, and available supports for parents of a child with autism, the main respondents were the parents obtaining services at the organizations or centers.

3.7. Population and Sampling Design

3.7.1. Source Population and Study Population

A source population refers to all possible cases of what we are interested in studying and a study population is the entire group of people to which a researcher applies/generalizes the result (Aron, Aron & Coups, 2008). The source population is all parents of a child living with autism in Addis Ababa, and the study population is parents who are receiving services from the study centers in Addis Ababa.

3.7.2. Sampling Design

Sampling design involves sample size and sampling techniques of the study (Oppong, 2013). A sampling design is a definite plan for obtaining a sample from a given population. It refers to “the technique or procedure that the researcher adopts in selecting items for the sample” (Kothari, 2004, p. 54). According to Corbetta (2003), sampling refers to the procedures in which

researchers extract a limited number of cases from the population through standard rules.

According to Neuman (2007), sampling depends on our understanding of the specific contexts based on selected cases, events, or actions. Similarly, Oppong (2013) stated that the aims of a particular study, as well as the features of the study population, influence the decision of which individuals and the number of individuals to be selected in a given research inquiry.

Along with the world views and research strategy adopted for this study, exploratory sequential mixed methods sampling design (QUAL → quan) was used to draw participants of the study (Graff, 2013). The sampling design was selected in a manner that compromises the requirements of the qualitative and quantitative samples, which is called the saturation/representativeness trade-off. Saturation goes with the qualitative sample and the representativeness concept applies to the quantitative sample (Teddlie & Yu, 2007). Thus, the principle of saturation was used to determine the sample size for qualitative data collection.

3.7.2.1. Sample Size Determination

Sampling in a mixed methods study may involve having a larger sample for the quantitative component and a smaller size for the qualitative (Teddlie & Tashakkori, 2009). The sample size in qualitative studies is often determined based on theoretical saturation or the point at which data will no longer bring additional insights to the research questions (Englander, 2012). Small sample sizes are the norm in qualitative research design as the analysis of large data sets may result in the loss of ‘potentially subtle tones of meaning’ (Collins & Nicolson, 2002). Similarly, in Patton’s (1990) view, all types of sampling in qualitative research focus on nominating relatively small samples even single cases, selected purposefully with a broad

general knowledge of the topic or those who have undergone the experience and whose experience is considered typical.

According to Kreuger and Neuman (2006), qualitative research is not mainly concerned with drawing representative samples, rather, it focuses on how the sample or small collection of cases, units, or activities illuminate social life. Samples (study participants) are selected based on their ability to clarify and deepen understanding of cases, events or actions, and rich knowledge of the research issue to provide good insight. In addition, qualitative research as stated by Hesse-Biber and Leavy (2011) has a logic concerned with in-depth understanding, usually working with small samples. Accordingly, this study used a non-probability sampling method specifically purposive sampling based on eligibility criteria, to identify cases that fit particular criteria and that could provide in-depth information about the research issue (Creswell, 2014). Then, for this study, 12 (twelve) in-depth interviews with parents and eight key informant interviews (i.e., two with the founders of the centers, four with the centers' teachers, and the rest two with the medical professionals working on autism in Zewditu Memorial Hospital) were conducted.

In a quantitative study, according to Triola (2010), if a population has a sampling frame, the sample can be determined using the formula for estimating a single population proportion. Therefore, given the sampling frame for the population under consideration, the sample size was determined based on a formula for a single population proportion. The level of significance was taken at 95%, ($Z_{\alpha/2}=1.96$), the margin of error was 5%, and since the previous prevalence rate of parents is not known; the maximum prevalence rate (0.5%) was used. To compensate for the non-response rate, 5% was added.

$$n = \frac{(Z \alpha/2)^2 P (1-p)}{d^2}$$

Where: $Z \alpha/2$ = is a probability coefficient for the desired interval or critical value at 95% confidence level of certainty [1.96]

n = minimum sample size determined

P = proportion of the population possessing characteristics of interest

d = tolerated margin of sampling error between the sample and population (5%)

$1-p$ = proportion of the population that does not possess the character of interest.

$$\text{Consequently, the sample size } n = \frac{(1.96)^2 0.5(1-0.5)}{(0.05)^2} = 384$$

Since the total population (N) is less than 10,000, we have used finite population correction factor (FPC) formula, as shown below:

$$nf = 1 + \frac{n_i}{N}$$

Where: nf = final sample size

n_i = initial sample size

N = total study population

$$nf = \frac{n_i}{1 + \frac{n_i}{N}} = \frac{384}{1 + \frac{384}{140}} = 103$$

Considering a 5% non-response rate, the final sample size was = 108. Therefore, the total sample size was 128 individuals (i.e., 20 for qualitative and 108 for the quantitative).

3.7.2.2. Sampling Techniques

Two sampling techniques are often mentioned in conducting quantitative and qualitative research. These techniques are probability and non-probability sampling techniques. For this study, the researchers used an exploratory sequential mixed-method strategy. Mixed methods

sampling techniques entail “the selection of units or cases for a research study using both probability sampling (to increase validity) and purposive sampling strategies (to increase transferability)” (Teddlie & Yu, 2007, p. 78). A probability sampling technique was used to select participants for the quan strand; whereas purposive sampling from the non-probability sampling technique was used to identify participants for the QUAL strand. These sampling procedures are separate and independent.

The purposive sampling technique appears helpful in conditions where researchers purposively select individuals on particular issues. Neuman (2007) extends discussion of two conditions that necessitate the utilization of purposive sampling techniques in research: (i) when a particular investigation requires in-depth studies; and (ii) when the researcher aspires to select unique and informative cases from the population. Consequently, purposive sampling was used for the in-depth and key informant interviews. In the selection of participants using purposive sampling, Kreuger and Neuman (2006) explain the use of judgment of an expert in selecting cases or the expert select cases with a specific purpose in mind. Accordingly, this research used purposive sampling technique, and participants were selected based on the inclusion/eligibility criteria of the study.

For the quantitative data, a multi-stage cluster sampling technique was used to select the participants. A multi-stage cluster sampling involves a sequence of stages (Hair, Money, Samouel & Page, 2007). In multi-stage sampling, the first stage often involves cluster sampling, whereas subsequent stages involve simple random sampling, stratified random sampling, and/or systematic random sampling (Makerere University, 2013). Cluster sampling is a sampling technique where the entire population is divided into groups or clusters. Clusters are natural groupings of people (Sedgwick, 2015). Therefore, in a multistage clustering procedure, the

researcher first samples groups or organizations to obtain names of individuals within groups/clusters and then samples within the clusters. Since both existing centers were (purposefully) included, the total sample size was proportionally allotted to the number of parents in the centers. After proportionally allocated to the center, the actual data were collected from the respondents by using a simple random sampling technique.

The following steps can elaborate on this approach:

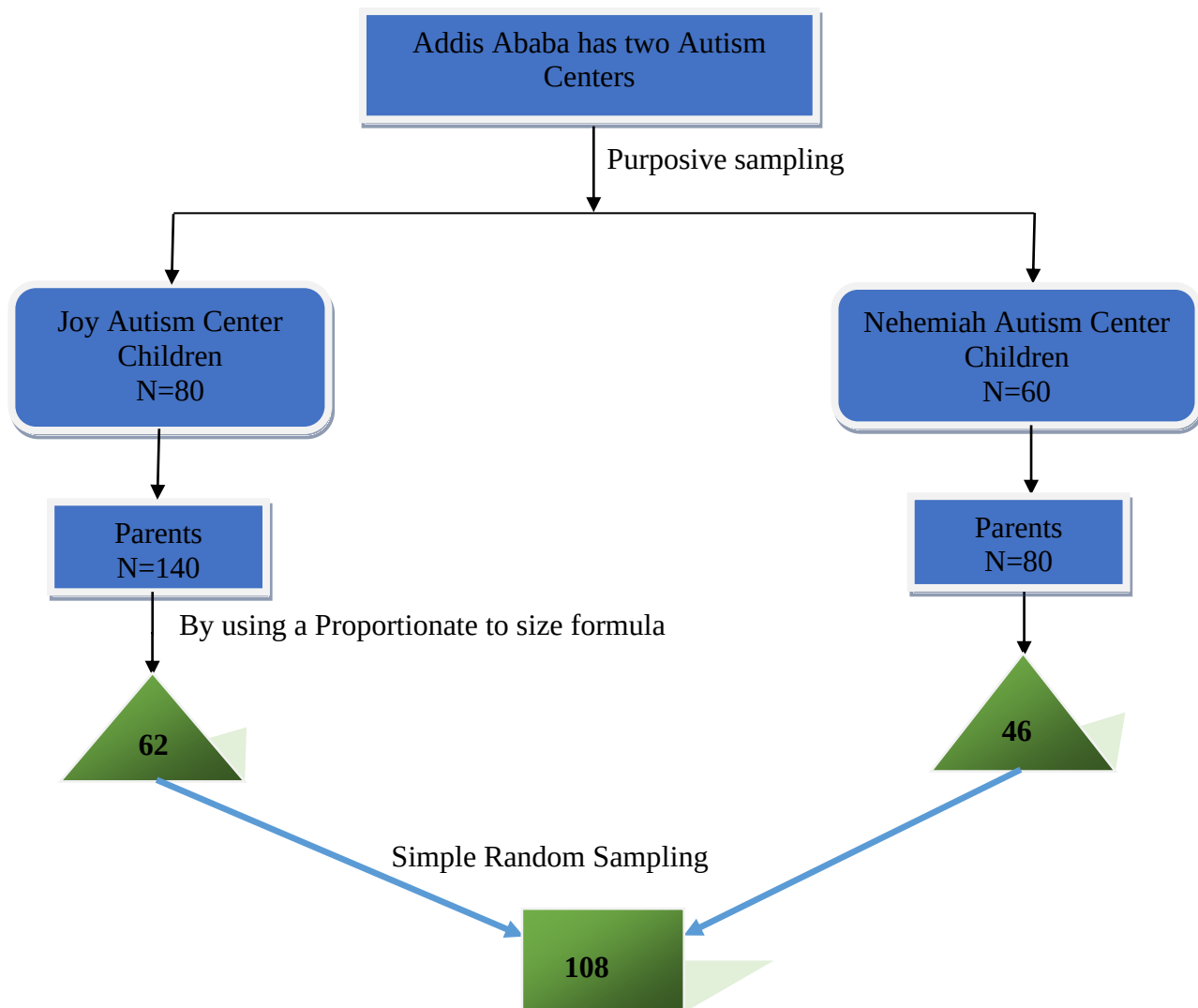
Step one: In Addis Ababa, there are two autism centers (Joy and Nehemiah Autism Centers).

Step two: A list of parents receiving service from the centers was compiled.

Step three: The required sample or respondents of the study was calculated using proportionate allocation to the number of parents in each stratum/center, using the calculated sample size ($n=108$) as presented in Figure 7. Then the actual sample was constructed (the data were collected from the respondents) using a simple random sampling technique.

For authors such as Corbetta (2003), a simple random sampling technique appears appropriate when the list of the units in the study is accessible. It was possible to access the lists of the parents from the respective study centers. Aside from accessing the lists of the parents, according to Cohen, Manion and Morrison (2000), “in simple random sampling technique, each member of the population under study has an equal chance of being selected from a list of the population” (p. 100). Such qualities marked the simple random sampling technique as the most appropriate technique to be used.

Figure 7: The schematic presentation of the sampling technique for a quantitative approach



3.8. Eligibility Criteria

3.8.1. Inclusion Criteria

Participants of the study were selected based on the following inclusion criteria:

- A parent having an autistic child and living for more than two years in Addis Ababa;
- Both parents together or a single parent can be part of the study;
- Parents having a child aged two and above. This particular age of a child was chosen based on the description provided by the diagnostic statistical manual for mental

disorders (DSM-5). The manual describes autism as a behavioral disorder that is usually manifested after a child turns two years old. Although in some cases, parents report having been aware of their child's situation since birth, generally the disorder is manifested after a child turns two years (American Psychiatric Association, 2013).

- d) Participants or parents who are willing to be part of the study; and
- e) Parents of autistic children who are receiving services from either the Joy or Nehemiah Autism Centers are set as eligibility criteria for the study.

3.8.2. Exclusion Criteria

The parent excluded from this study was:

- a) Parents not having a child living with autism;
- b) Parents who are not Addis Ababa residents (living less than two years in Addis Ababa);
- c) Parents having a child less than two years of age;
- d) Parents who are not willing to participate in the study; and
- e) Parents who are not currently receiving services from the centers.

Therefore, the study participants were the parents of children with autism who fulfill the inclusion criteria and are willing to participate in the study.

3.9. Variables of the Study

From the challenges faced by parents, ***stress*** in caring for a child with autism was the dependent variable (DV) of the study, and ***stigma*** was the independent variable (IV). ***Coping mechanisms*** of parents (Seeking Spiritual Support, Reframing, Mobilizing Family, Passive Appraisal and Acquiring Social Support) were the mediating variables of the study.

3.10. Methods of Data Collection

Methods of data³collection– involve the tools utilized for generating data (Sarantakos, 1996). In the vein of philosophical perspectives and research strategies, this study applies the combinations of various data collection methods. Babbie (1990, p. 27) justified that, “... the examination of a given social phenomenon is often best accomplished through the use of ... different methods. Social researchers, who limit themselves to a single method... severely, limit their ultimate ability to understand the world around them.”

Methods for data collection were proposed based on the philosophical underpinnings of the inquiry (Smith, 2012). For instance, in qualitative studies, interpretive philosophy favors’ in-depth interviews, key informant interviews, FGDs, observation methods, and document reviews, to explore a diversity of attitudes, rather than their intensity (Merriam, Tisdell, Askews, & Holts, 2016). In contrast to qualitative studies, in quantitative studies, positivism commonly relies on random sampling and structured data collection instruments, such as questionnaires and structured interviews, and attempt to fit diverse experiences into predetermined response categories (Smith, 2012). In a mixed-method study, data are collected using both qualitative and quantitative methods, which vary in their procedure, according to the specific mixed method design (Creswell, 2014). To illustrate more, in an exploratory sequential mixed method design, the researcher collects the quantitative after qualitative data (Creswell & Clark, 2007).

³ The concept of ‘data’ has a Latin origin and indicates ‘things given’. Data exists in several forms encompassing the collection of information via questionnaires, interviews, observational checklists, documentary records, statistical information, and oral histories (Turner, 2006, p. 121). Mwanje (2001, p. 7) complemented that, “the bulk of the data handled by social scientists are those about human behavior, attitude, distributions, patterns, and spatial interactions.”

Methods of data collection used in this research were in-depth interviews, key informant interviews, and a structured questionnaire. The in-depth interviews and key informant interviews were used to gather the qualitative data, while the structured questionnaire was used to collect the quantitative data. The close-ended questionnaire was used to generate statistical data. In the case of a large sample size, the questionnaire was assumed to be an appropriate means of collecting quantitative data (Creswell, 2007). According to Longfield (2004), close-ended questions provide respondents with a fixed set of alternatives from which to choose, while open-ended questions encourage informants to determine the direction of the response and encourage them to reply at length.

The method of data collection in qualitative research falls into four categories: “Observation, interviews, documents, and audiovisual materials” (Creswell, 2014, p. 188). To generate qualitative data, in-depth interviews with twelve parents and eight key informant interviews with the two founders, teachers of the centers, and medical professionals were conducted using open-ended questions. Open-ended questions provide an opportunity for participants to freely share their views and the social meanings they attributed to their experiences. In line with this, Smith and Osborn (2007) stated that unstructured interviews allow the researcher and participant to engage in a dialogue whereby the investigator can probe interesting and important areas; allow greater flexibility of coverage to go to novel areas; and produce richer data. Turner (2010) indicated an in-depth interview provides detailed information about participants’ experiences and viewpoints of a particular topic. Tong, Sainsbury, and Craig (2007) also stated that during the interview, the researcher could further clarify questions to direct the participants for further exploration. In this study, in-depth interviews, key informant interviews, and structured questionnaires were used with the parents, founders, teachers of the

centers, and medical professionals to comprehend the challenges, coping mechanisms, and available support for parents of a child with autism.

3.11. Instruments and Measurement of Data Collection

The instruments of data collection were designed to gain sufficient central ideas of the study, which in turn enables the respondents to answer the research question of the study in general. Authors like Colton and Covert (2007) defined data collection tools such as a questionnaire as “mechanisms used to collect factual information, support observations, or assess attitudes and opinions of units... in a given study” (p. 6). In an attempt to address the research question, different tools/instruments of data collection were used. Given the philosophical foundations and design of the study, pragmatism and mixed-method, multiple data collection tools were employed to collect both qualitative and quantitative data. A structured questionnaire was used to collect the quantitative data and an in-depth interview and key informant interview guides were employed to collect the qualitative data. Hence, the details of the instruments were presented as follows.

3.11.1. Unstructured Interview Guides

3.11.1.1. In-depth Interview Guide

An in-depth interview was employed since it is appropriate “to obtain detailed information about the issue to be studied from the individual perspective using his/her expressions” (Kalof, Dan, & Dietz, 2008, p. 120). Crano and Brewer (2002) shared that, “...interview occurs when the nature of the research issue demands a personal and interactive method of data collection” (p. 223). Marckzyk, DeMatteo and Festinger (2005) noted that interviews are relatively common ways of collecting data in research. Similarly, Burns (1999)

noted that the strength of unstructured interviews tends to be one of the most favored by researchers as it allows respondents to express themselves at some length yet offers enough shape to prevent aimless rambling and helps researchers to obtain themes and topics which may not have been anticipated while designing the interview.

Qualitative research primarily utilizes “unstructured or semi-structured data collection tools to gather the required information using open-ended questions” (Zegeye et al., 2009; & Crotty, 1998 as cited in Creswell, 2009, p. 8). Cohen et al. (2011) argue that open-ended questions are more flexible, and provide more freedom to answer, which is useful when there is no pre-emptive potential answer to the question. According to Yeraswork (2010), in this method of data collection “the interviewee is allowed to talk freely about various aspects of a topic. In-depth-interviews or extended interviews provide richer material than is usually available from surveys” (p. 28). To guide the interview session, an interview schedule was used in the data collection process. The open-ended questions were developed in English and then translated into the Amharic language. The prepared in-depth interview guide was commented on and reshaped by advisors and peers (Ph.D. students) to assure that each item was in line with the stated research objectives (see Appendix-B).

In this study, an individual in-depth interview was conducted with parents. Questions were prepared to cover the main areas of interest. In-depth interviews played a key role in allowing participants to freely communicate about challenges, coping mechanisms, and supports for parents of a child with autism. The length of each interview ranged from one and a half to two hours. They were audio-taped to get all the detailed information that the researcher intended to investigate for a detailed analysis and to ensure that the interviewees’ responses were captured in their terminology and expressions.

3.11.1.2. Key Informant Interview (KII) Guide

Key informants are participants whose social positions give them specialist knowledge about other people, processes or happenings that is more extensive, detailed or privileged than ordinary people, and who are particularly valuable sources of information to a researcher (Payne, & Payne, 2004). The founders of the organizations, teachers in the center, and medical professionals were the key informants. These individuals are key, because of their expertise and position; they were also running the organization in close contact with staff, children, and parents. These respondents have provided comprehensive information on the supports offered to parents by the centers. To guide the key informant interviews, a prepared checklist/key informant interview guide was used. The developed open-ended questions in the key interview guide were commented on and reshaped by advisors and peers (Ph.D. students) to assure that each item was in line with the stated research objectives (see Appendix-C).

3.11.2. Structured Questionnaire

A structured questionnaire is a set of questions used to gather information from respondents using a close-ended type of questions (Kothari, 2004). The questionnaire uses pre-coded questions with a well-defined skipping pattern. Most quantitative data collection used structured questionnaires to generate statistical data (Acharya, 2010). To gather the quantitative data, a structured questionnaire was employed. A structured questionnaire allows all the participants to respond to the same questions, as participants are offered the same options on each statement (Saunders, Lewis, & Thornhill, 2009).

The questionnaire method has many advantages compared to the unstructured interview method. Firstly, it generates answers from a large group of participants at a low cost; secondly,

questionnaires provide respondent anonymity; and finally, there is less interviewer bias (Polit & Beck, 2004). In other words, questionnaires provide a relatively cheap, quick, and efficient way of obtaining large amounts of information from a large sample. Close-ended items are easy for data management (tabulation), objectivity, and suitability to keep respondents on the subject of discussion.

For the structured questionnaire with parents of children with autism, the socio-demographic characteristics (part-one), Child-related information (part-two), and perceptions of parents about autism (part-three) of the questionnaire were developed by the researchers from available literature and personal experience. The questionnaire was commented on and reshaped by advisors and peers (Ph.D. students) to assure that each item was in line with the stated research objectives.

Abidin's (1995) 36-item Parenting Stress Index-Short Form (PSI-SF), 14-item Family Interview Schedule-Stigma Scale (FIS-SS) from Sartorius & Janca (1996), the 30-item Family Crisis Oriented Personal Evaluation Scales (F-COPES) developed by McCubbin, Olson, and Larsen (1987), and the 19-item Family Support Scale (FSS) developed by Dunst, Trivette and Jenkins, (2007) were standardized tools adopted from the literature. The questionnaires were checked by advisors and peers (Ph.D. students) to assure that each item was in line with the stated research objectives. After the questionnaire was adopted, translation was carried out by a language expert together with the researchers. The translated questionnaire was later retranslated back by another language expert to see the translated versions' congruence with the original English questionnaire. Brief descriptions of the structured questionnaire are provided in the following section.

3.11.2.1. Socio-demographic Characteristics Questionnaire (DCQ)

A 14-item (parent-related) and 9-item (child-related) socio-Demographic Characteristics Questionnaire (DCQ) was designed for this study to acquire information on parent and child demographics (Appendix-D). These questionnaires were developed by the investigators and included questions on the child's age, gender, age at diagnosis, education level, and parents' age, gender, marital status, religion, education, occupation, and household income. A study by Zablotsky et al. (2013) suggests that socioeconomic status may predict stress and other challenges like depression and anxiety in parents of children with ASD; thus, family income was included in the demographic questionnaire. This short survey was collected to provide descriptive information on both the children and their parents.

3.11.2.2. Parenting Stress Index-Short Form

The Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1995) is a 36-item scale used to measure parental stress (Appendix-D, Part-III). The PSI-SF is the most widely used instrument for measuring parenting stress of parents who have children with ASD to identify various forms of stress associated with parenting (Abidin, 1990; Zaidman-Zait et al., 2011). It is an abbreviated version of the 120-item Parenting Stress Index (PSI) (Loyd & Abidin, 1985). Questions on the short-form were selected through a factor analysis for a more efficient and less time-consuming means of collecting data on parental stress. Stress is measured/rated on a five-point Likert Scale ranging from strongly disagree (1) to strongly agree (5). This measure yields scores on three subscales consisting of 12 questions each: (a) Parental Distress (PD), (b) Parent-Child Dysfunctional Interaction (P-CDI), and (c) Difficult Child Characteristics (DC).

The respondents' raw scores were converted into percentile scores. A score ranging between the 15th and 80th percentile is considered typical (normal) while scores equal or greater than the 85th percentile (the clinical cut-off-point) is considered high (Abidin, 1995). Scores on the three subscales (PD, PCDI, and DC) all range from 12-60, while the total stress index ranges from 36 to 180. Higher numbers/scores indicate greater distress.

Good evidence of content validity (Burke & Abidin, 1978; Kazak & Marvin, 1984), concurrent and construct validity (Abidin, 1983; Loyd & Abidin, 1985), and factorial validity (Abidin, 1983) have been reported. The three scales and the total scale have shown high internal consistency (Abidin, 1995). The total stress index's coefficient alpha reliability is .96 (Abidin, 2012), and the total stress index yielded a high internal consistency of $\alpha = .95$ (Reitman, Currier, & Stickle, 2002). In the present (the researchers) sample, alphas ranged from .84 to .91 for parents across the three scales and the total scale.

3.11.2.3. Family Interview Schedule-Stigma Scale (FIS-SS)

The family's experience of stigma in the community was measured using an adapted version of the Family Interview Schedule-Stigma Scale/FIS-SS (Sartorius & Janca, 1996). The FIS-SS includes 14-items about the family's experience of stigma in the community (see Appendix-D, Part-IV). Each item was rated on a four-point scale where the intensity of experiencing stigma in the community was described as: a lot (a score of 3), often (a score of 2), sometimes (a score of 1), and not at all (a score of 0). To assess the distribution of responses between groups, a total score was computed by summing the item scores, with a minimum score of 0 and a maximum score of 42. The internal consistency of this adapted FIS stigma scale is high (Cronbach's Alpha = 0.92) (Sartorius & Janca, 1996).

3.11.2.4. Family Crisis Oriented Personal Evaluation Scales/F-COPES

The F-COPES (McCubbin, Olson, & Larsen, 1987) is a 30-item questionnaire used to assess ways that families cope with problems/challenges (see Appendix-D, Part-V). The measure uses a 5-point Likert Scale with responses ranging from strongly disagree (1) to strongly agree (5). This measure assesses perceptions of parents regarding how they cope with the challenges. The measure has five subscales: acquiring social support (9 items), reframing (8 items), seeking spiritual support (4 items), mobilizing family to acquire and seek help (4 items), and passive appraisal (5 items). This instrument was designed to measure internal and external coping strategies used by the parent. Higher scores indicate more positive coping and problem-solving strategies in times of crisis.

This measure has good internal consistency and an overall alpha of 0.82. The overall test-retest reliability is 0.81. The alphas for the subscales range from .61-.81, and the test-retest values range from .61-.95 (McCubbin, Olson, & Larsen, 1987). Internal consistency of this scale was tested with a sample of 80 people in Addis Ababa and the result revealed .91 alpha levels (Soliyana, 2015). This measure was used in this study to determine if (the extent to which) the parent/family uses effective/positive coping strategies to deal with the challenges they might experience as a result of raising a child with autism.

3.11.2.5. Family Support Scale (FSS)

The Family Support Scale (FSS) (Dunst et al., 2007) is a 19-item scale that measures parents' perceptions of support resources made available to parents/families raising a young child living with any disability (see Appendix-D, Part-VI). The original version of the Family Support Scale contained 18 items (Dunst, Trivette, & Jenkins, 1986a); the newer version

contains 19 items adding “neighbors” to the list of people or groups that are helpful to families raising young children (Dunst et al., 2007). In addition, the scale provides two open-ended items for parents to write other sources of support not included in the 19-items. The scale has been empirically tested with parents of children with ASD (Bromley et al., 2004; Hastings & Johnson, 2001).

The FSS assesses the parent’s perception of support during the past 3 to 6 months on a 5-point Likert scale. The parent rates each source of support on a 5-point Likert scale ranging from ‘not at all’ (1) ‘to extremely helpful’ (5). The parent’s responses on the total scale range from either 0-95 (0-105 if the respondent fills in the 2 open-ended items). Analysis of the scale’s total support index reliability resulted in a Cronbach’s alpha coefficient of .79 (Dunst et al., 2007). On the other hand, Hanley, Tasse, Aman, and Pace (1998) investigated the psychometric properties of the Family Support Scale in a sample of 224 parents of preschool children with any disability. The reported internal consistency for the total score was .85. Test-retest reliability was established as parents in this sample completed the FSS two weeks later. The total alpha score was .88. In our study, the total score of the alpha was .76, with the subscales ranging from .80-.91 (see Table 2).

3.12. The Procedure of Data Collection

In a sequential exploratory mixed-method strategy, quantitative data collection and analysis is the second phase that builds on the results of the first qualitative phase (Creswell, 2008). The data were collected sequentially; the quantitative data were collected after the qualitative data collection and analysis. For the qualitative data, the researchers scheduled both the in-depth interviews and key informant interviews after meeting all the respondents (in-

person) to make sure that they were willing to provide information. The researchers were engaged with participants and built a good relationship before the interview. The researchers feel that this rapport creation before the interview may lead to greater openness and willingness to engage with the researchers during the interview process. Afterward, depending on their preferences, the participants were interviewed at a convenient time and location. On the other hand, the structured questionnaire for the quantitative data was adopted from the literature. The data collection began after a short meeting with participants/parents to acquaint them with the purpose of the study and to obtain informed consent. After obtaining their consent or signing a written consent form (Appendix-A), the interviews were conducted at a convenient time and place. Generally, all these instruments were designed to explore the challenges, coping mechanisms, and available support for parents of a child with autism in Addis Ababa.

3.13. Methods of Data Analysis

Data analysis is defined as the process of converting raw data into meaningful and useful information (Creswell, 2014). Data analysis “involves examining, categorizing, tabulating, or otherwise recombining the evidence, to address the initial proposition of a study” (Yin, 1989, p. 105). Similarly, for McNabb (2008), data analysis is the process of evaluating data using analytical and logical reasoning to examine each component of data. Collis and Hussey (2003) argue that the data analysis approach is guided by and depends on the epistemological perspectives, approaches to the problem, and research questions.

For this study, the researchers have adopted sequential mixed methods data analysis (Graff, 2013) that involved ‘QUAL’ analysis of data using thematic analysis and ‘quan’ analysis of data using statistical techniques. The two analyses were conducted sequentially independent

of each other and provide information about the phenomenon through connecting or integrating the findings from both the 'QUAL and quan' analysis. In mixed-method studies, data analysis involves various analytical techniques that apply to both quantitative and qualitative data, as well as to the mixing of the two forms of data, concurrently or sequentially, in a single or multiphase approach within the research project (Tashakkori & Teddlie, 2003). Thus, Creswell and Clark (2007) argue that in a sequential mixed-method study, data should be collected and analyzed sequentially, and then connected at the interpretation level.

Data analysis in qualitative research consists of preparing and organizing the data for analysis, then reducing the data into themes through a process of coding and condensing, and finally representing the data in text, figure, or a discussion (Creswell, 2007). In qualitative research, the process of data analysis proceeds simultaneously with data collection (Creswell, 2014; Hesse-Biber & Leavy, 2011). Therefore, the collected data (including notes, audio, and memos) through the in-depth interviews and key informant interviews were transcribed and read. During the process of transcription to maintain confidentiality, pseudonyms were given to each respondent. After transcription, the researchers would understand, identify, and organize possible codes, themes, and categories. The researchers employed coding and thematic developments that are the most widely used analytic procedures (Padgett, 2008).

Then, the responses were thematically categorized and narrated to make responses understandable and coherent. Thematic analysis is a commonly used means of analyzing qualitative data, which is not aligned with any particular epistemology or methodology (Vaismoradi, Turunen, & Bondas, 2013). Hence, a thematic data analysis was employed for this study. According to Reissman (2005), thematic data analysis is one of the qualitative data

analysis methods which seeks to understand human experience and/or social phenomena through the form and content of stories narrated by individuals.

The data collected through structured questionnaires were analyzed using SPSS version 26.0 and Amos version 23.0 softwares. Accordingly, the collected data were cleaned and checked for completeness and then coded and entered into SPSS software version 26.0. To describe the data, both descriptive and inferential statistical procedures were computed and presented in tables and graphs. Since this study involved both the collection and analysis of qualitative and quantitative data, the mixing occurred by connecting the two datasets. Interpretation of the data was carried out after the quantitative analyses. Following a report or finding of quantitative data, interpreting the datasets was conducted as illustrated in Figure 8.

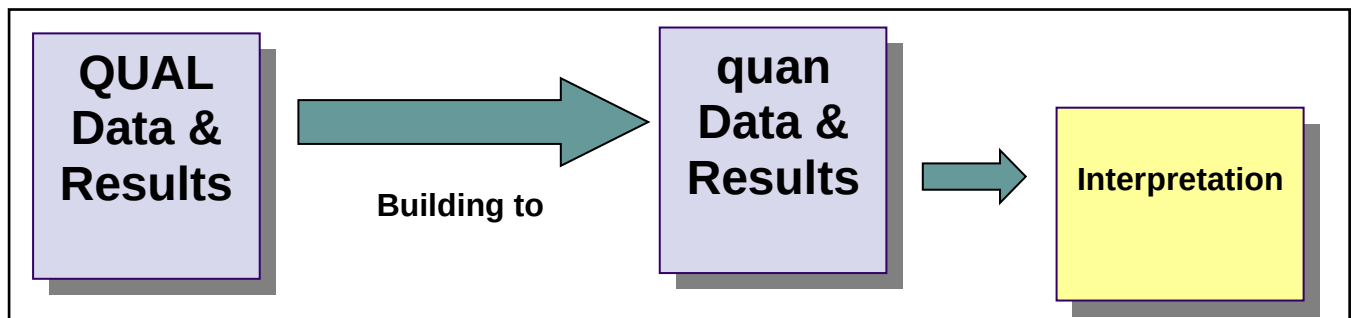


Figure 8: The Schematic Presentation of how a Mixing occurs in a Sequential Exploratory Design (Adapted from Creswell, 2009, p. 173).

According to Creswell and Clark (2011), mixing involves connecting both the qualitative and quantitative findings to discover a new set of interpretations that were used to answer the research questions. Hence, the researchers connected the information obtained from the research participants through in-depth interviews, key informant interviews, and structured questionnaires to arrive at a conclusion on the challenges, coping mechanisms, and supports for the parents of a child with autism.

3.14. Data Quality Assurance

Researchers make every effort to present valid/trustworthy and reliable/consistent findings to readers. However, since qualitative and quantitative research approaches differ in their basic assumption, the technique used to assure trustworthiness in each of the research approaches also varies. The main aim of qualitative research is to explore the perception of individuals regarding certain social issues instead of quantifying a phenomenon (Green & Thorogood, 2014). As a result, in this study, the application of the main concepts of validity/trustworthiness, and reliability/consistency are constructed based on the assumptions of mixed research.

3.14.1. Reliability

Reliability is concerned with “...*the consistency or stability of a measure; if (the study) were to be repeated, would the same result be obtained?*” (Robson, 2002, p. 93). The widely accepted definition of reliability is the repeatability (consistency) of the result. Hence, to test the reliability of measuring tools employed for the quantitative data, the most common technique used to assess the scale’s reliability is Chronbach alpha statistics, which identifies to what extent items swing together as one set. Low Chronbach alpha values mean the items do not capture the same construct, and high values of Chronbach alpha indicate the items well measure and reflect the construct. Ideally, the Chronbach alpha should be over 0.7 to produce a reliable scale (Burns & Burns, 2008). Accordingly, the reliability of the items in the tools was assessed using the Chronbach alpha reliability test statistics (See Table 2).

When other researchers conducting the same study using a similar method repeat the same result, the results are viewed as reliable. However, social occurrences examined through

qualitative methodologies are often difficult to repeat. Data are dependent on the respondents' interpretation of the questions. This can change due to personal or environmental factors. For example, a parent's response to the same question might change if their child's behaviour has deteriorated, if services are decreased or ceased, or even as a result of being in a different frame of mind, which could have a potential impact upon replicability. Hence, qualitative research focuses on producing results consistent with the collected data instead of the repeatability of a study (Merriam, 1995). In qualitative research, a clear explanation of the concepts and procedures of the study is important in assuring the reliability of the study (Pilnick & Swift, 2011).

To ensure reliability, the tools for data collection were pilot-tested, and further, all interviews were tape-recorded to present more reliable evidence and avoid bias, which might happen if the researcher attempted to remember the conversation. As Gray (2004, cited in Helen, 2016) asserted, "in terms of reliability, it is fairly obvious that taped conversations will tend to present more reliable evidence than hastily written field notes" (p. 65). Seidman (2006) also indicated tape-recording works most reliably with the words and thoughts of participants and to help researchers maintain their original data. Seidman further argued that if something is not clear in a transcript, researchers can return to the source and check for accuracy, and if they are accused of mishandling their interview material, they can go back to their original sources to demonstrate their accountability to the data. Tape-recording also benefits the participants by assuring that participants' explanations are fully captured (a record of what they have said), which gives them more confidence that their words were treated responsibly. Thus, a clear explanation of the concepts, methods and procedures, pilot-testing, and tape recording were used to ensure the reliability of the qualitative part of the study.

3.14.2. Validity

Validity, as defined by Long and Johnson (2000), is ‘*the accuracy of measure*’. An instrument is said to be valid when it measures what it was designed to measure. Validity is conceptualized as the degree to which “a method investigates what it is intended to investigate” (Kvale & Brinkmann, 2009, p. 246). Babbie (2008) also added a complementary view that “...validity refers to the extent to which an empirical measure adequately reflects the real meaning of the concept under consideration” (p. 160). In qualitative research, some scholars apply alternative terms such as ‘trustworthiness or truth-value’ to refer to validity. The concept validity, within the confines of qualitative research, is used to mean trustworthiness (Silverman, 2000). It refers to the extent to which the data collected give a true measurement or description of social reality. Thus, the conditions surrounding the production of the data should be revealed clearly and truthfully (Hirsjärvi et al., 1998 as cited in Nieminen, 2010). Qualitative researchers utilize different methods to enhance the truth-value of findings by presenting findings acquired from various shreds of evidence (Noble & Smith, 2015). The trustworthiness of the tool was also checked by conducting a pilot study on 10% of the sample. Generally, some of the methods that are used to enhance the validity and reliability of this study were *member checking, peer validation, pilot-testing, and triangulation*.

Member checking: Member checking (respondent validation) was used to ensure the data was consistent and trustworthy. During the interview, member checking was done by the researchers restating, summarizing, or paraphrasing the information received from a respondent to ensure that what they have heard or recorded was equivalent. Newton (2010) stated that member checking is a fundamental process that affirms participant responses and validates emerging themes, which enhances the trustworthiness of the study. Member checking is a

strategy that can be used to improve the credibility of a study. Member checks entail presenting the research data to participants to check for accuracy and ensure there is no misrepresentation of information (Krefting, 1991). To enhance the credibility of this study, the researchers summarized what was said by the participants and asked if the records reflect their viewpoints at the end of each interview session as a method of member checking.

Peer Validation: A peer (a Ph.D. student) and the researchers reviewed the responses to all questions. Then, both of us developed a series of categories into which the responses appeared to fit. We compared our categorical listings, merging similar categories, and separating different categories coming up with an agreed-upon set of categories for each question. We sorted the responses independently into one or more of the agreed-upon categories. When there was a disagreement, we discussed the responses and the categories involved until an agreement was reached. Where one reviewer assigned a response to more than one category and the other reviewer did not, the responses were discussed to determine the categories in which they would be placed.

Pilot Testing: Purpose, Usefulness, and Lessons. All instruments were pilot-tested on 10% of the sample. The tools were pilot-tested to check for clarity, understandability, acceptance, and adequacy. Based on the result of the pilot test, the unclear and blurred questions were modified and Chronbach's alpha levels were calculated for the structured questionnaire. Data completeness and consistency were also checked daily, and the collected data were cleaned and compiled by the principal investigator.

The main purpose of the pilot study was to test the data collection instruments. Pilot-testing practices further refine, assist to modify, and reformulate the items in a questionnaire.

Stockton, van Maris and King (1999) suggested that “pilot testing is a crucial step in conducting a survey” (p. 19). The practice generally verifies, among others, the consistency, concepts, logical flow, and connections among the questions.

Pilot testing provides valuable information about instrument utility and assists the identification and correction of factors associated with instrument design and format that can lead to problems during the data collection (Colton & Covert, 2007). Similarly, Bethlehem (2009) contended that “numerous aspects of a questionnaire should be tested... the most important aspect is the validity of the questions” (p. 58). Hence, it was also used to produce data for demonstrating validity and reliability, which ultimately helps to ascertain whether the instrument is producing the desired information.

Lessons Learned from the Pilot Testing: Pilot testing was conducted to avoid any possible mistakes in the questionnaire and to determine the level of respondents’ understanding of the questionnaire. We conducted a pilot study through questionnaires distributed to 10% of the sample size (11) respondents for the quantitative part. On the other hand, two individual in-depth interviews and two key informant interviews were conducted for the qualitative part. The respondents of the pilot study were drawn from teachers in the centers, medical professionals, and the parents of a child receiving services from Joy and Nehemiah Autism Centers. The participants of the pilot study were not included in the final data collection to avoid double counting.

Pilot-testing practices revealed gaps in the constructed interview guides, questions and items contained within the guides. In the items, lack of clarity with a few concepts was detected during the pilot testing. The testing informed clarification of vague concepts to avoid dubious

responses among the respondents. The assessments confirmed the presence of difficulties in apprehending concepts in the Amharic instrument as compared to ideas in the English instrument. Hence, we have observed that there was a low tendency of understanding the questionnaire. Accordingly, the reviews of the items on the pilot testing on interview guides and questionnaire lead to the simplified version of the final instrument.

Taken as a whole, the pilot testing created an opportunity for the re-arrangement, refinement, and modification of the items in the tools. The testing exercise showed the presence of gaps in the instrument. With the intent to fill gaps identified in the instruments, the length of items and conceptual difficulties were further refined and adjusted to the contexts on the ground. The insertion of additional questions and removal of a few questions were part of the lessons and the modifications that occurred through the pilot-testing exercises. Therefore, the necessary amendments were made depending on the results of the pilot study, and consequently, the response format, language use, and the content of the questionnaire and interview guides were also improved.

Triangulation: The other method that was used to ensure rigor in this study is triangulation. Triangulation involves a combination of methodologies to study the same research problem (Onwuegbuzie & Leech, 2007). Triangulation, according to Brink (1993), is the use of multiple data sources, methods, and approaches for the study of a single phenomenon and checking the correspondence among them. In using triangulation, researchers went through a systematic process of employing various data collection methods. As a result, several forms of evidence were presented from different data collection methods instead of a single point of view from a single method (Creswell, 2014). However, data gathered using different methods is not

aimed to produce similar findings from each method. It is rather used to provide multiple views of the issue being studied (Barbour, 2001).

The researchers employed triangulation to represent the phenomenon as accurately as possible by corroborating evidence. The researchers employed three types of triangulations in this study (Denzin, 1973): (a) *Methodological triangulation*, both quantitative and qualitative methods were used. (b) *Data triangulation*, which was conducted through the collection of data using different methods. The methods used to collect data were in-depth interviews, key informant interviews, and questionnaires. (c) *Peer or Investigator triangulation*, which refers to the use of more than one researcher to gather and interpret data.

Triangulation is an important strategy in strengthening the findings of a study in mixed research. The employment of multiple methods of data collection plays a key role in presenting diverse realities and minimizing researcher bias (Bashir, Afzal, & Azeem, 2008). Moreover, the use of multiple methods enhances in-depth knowledge regarding a phenomenon and allows the researcher to produce rich data (Hussein, 2009). Another way that data triangulation was used in this study is through the collection of data from multiple sources. Accordingly, in addition to parents of a child with autism, data were also collected from the founders of the organization, teachers in the centers, and medical professionals.

3.15. Ethical Considerations

Ethical considerations are a set of norms and principles that the researchers follow and apply (Babbie, 1990). The American Psychological Association [APA] (2010) provided ethical standards to guide the research process and activities. We have adhered to the APA ethical standards that include obtaining appropriate institutional approval before conducting a study;

obtaining participants' informed consent, including consent for audio or visual recordings; informing participants about the nature of the study, voluntary participation, and the right to withdraw from the study at any time without retaliation (APA, 2010). Ethical issues identified by Lipson (1994) were "informed consent procedures, confidentiality, and benefits of research to participants over risk" (as cited in Creswell, 2007, p. 141). In Ethiopia, national ethical clearance for research was established in 2014. Even though there are various levels of ethical approval in Ethiopia, the majority are applicable for large-scale projects instead of a Master's or Ph.D. study at the individual level (Cochrane, 2018).

The primary task of the researchers was obtaining approval of the proposed research from the Graduate School of Social Work, Addis Ababa University. Once the school approved and permitted the study to continue, the next step was obtaining the informed consent of the individuals participating in structured questionnaires, in-depth interviews, and key informant interviews. Before commencing the interviews, the participants were given clear information about the purpose of the study. As stated in the informed consent form, participants were informed that participation is voluntary and that they had a right to withdraw from the study at any time. They were well-versed that there would be no consequence/risk by being a participant in the study. In addition to this, the privacy, anonymity, and confidentiality of the respondents were also shielded by using pseudonyms. Therefore, in the administration of the instruments, APA's ethical considerations were considered and based on this, participants were clearly informed about the purpose of the study, their consent was sought, privacy was respected, and they were guaranteed confidentiality of their responses.

3.16. The Role of the Researchers in the Study

The role that the researchers play in different parts of the study has epistemological and axiological implications for the process as well as the outcome of the research (Collis & Hussey, 2003). This study has used an exploratory sequential mixed strategy and the researchers played different roles in the qualitative and quantitative components of the study. In the quantitative component, data collection were conducted using a structured questionnaire and the researchers played a minimal role and had a very limited relationship with the respondents. The researchers, therefore, did not have the room to influence the data collection process and its outcome. As the data analysis was conducted using statistical tools (IBM SPSS version 26) and the results were interpreted based on the established statistical results, the personal values of the researchers had no room to influence the analysis and interpretations.

Qualitative research, on the other hand, opens room for the interaction of the researchers and respondents (Creswell, 2009). During the data collection through in-depth and key informant interviews, researchers played a more participatory role (active engagements) due to the nature of the issues being addressed and in the process established relationships with some of the participants in the key informant interview. The relationship with the other respondents in the interview was also more interactive due to the nature of the questions and the long time the researchers had with each respondent during the interviews. These practical realities of the qualitative study posed the possibility of bias in the interview process and outcomes.

Despite the above risks for bias, efforts were made to eliminate bias as much as possible. Except for the informal interaction of the researchers with the interviewees and the relationship that was developed during the interviews, the researchers did not have any personal or

professional interest that tempted them to bias the process and outcome of the study. More importantly, extensive verification procedures, including triangulation of data sources, peer-validation, member checking, and writing thick and rich descriptions of the issues under consideration were used to make the role of the researchers negligible in terms of influencing the direction of the findings.

3.17. Field Experiences and Challenges faced during the Fieldwork

Sarantakos (1996) contended that field research provides contexts for probing social life in its natural setting. The field research generates substantial experiences, with both unexpected encounters and genuine collaborations having cropped up in the field. The researchers have made recurrent visits to the study sites, particularly the Joy and Nehemiah Autism Centers, for preliminary reconnaissance. Those preliminary visits helped the researchers to carry out informal interviews; build rapport with the people in the institutions; and to identify key informants or individuals that grip relevant positions in the centers for the study.

Individuals in the institutions contacted during the fieldwork rendered extensive collaborations. The researchers' witnessed and appreciated the friendly approaches of sympathetic individuals in the institutions. Indeed, far beyond inviting coffee and cocktails, the sympathies provided by those involved individuals were backbones in undertaking the data collection. A generous provision of documents, processing of letters, active participation in the discussions, and warm reception to their offices were also encouraging collaborations rendered by the founders of the centers. The fieldwork further built and added the existing personal treasures of the researchers by constructing new webs of network and enriching social capital.

Challenges Faced During the Fieldwork: Reiteration is a normal phenomenon in the process of compiling this dissertation. More specifically, typical reiteration prevailed during the data collection processes. Refusal to be tape-recorded, particularly by three of the in-depth interviewees was one challenge in point. Some in-depth interviewees' altered tune of speech (unusual voice), difficult to hear after the record were declined from the interviews altogether.

Time management was another troublesome issue, mostly due to our culture of managing time and appearing late for appointments. In almost all cases, the researchers had to wait long hours for the interviewees to come. As a result, those who appeared earlier often came after 30-45 minutes of our appointment time. Another challenge was the question 'what is in it for me?' from respondents. One of the qualitative respondents who was tired by repeated questions of graduating students from different institutions frankly asked, "If your research will not come back to me in the form of a project for our children, why do I waste my time?" He further stated, "most of the time studies are put on the shelf of Addis Ababa University or other institutions and our challenges remain the same whether we are studied or not. Of course, you are a graduating student whom I would provide information, but I want you to loudly voice it to the government and concerned bodies". Then, after a discussion on this point (especially on the purpose of graduating student research) for some time, the willingness and open sharing of experiences gradually grew out of the context and we had a really fruitful discussion time. Generally, issues related to refusal of tape recording by a few participants, lack of proper management of time, and pressing needs for the results/tangible effect of the study on the life of the parents were major factors that posed challenges to the smooth execution of the fieldwork.

3.18. Limitations of the Study

Despite the contributions, it is important to note that this study has some limitations. Firstly, the study population comprises parents of children with autism living in Addis Ababa and who are provided with care and support from the two institutions (namely, Joy and Nehemiah Autism Centers). This is due to the lack of an organized database about the location and number of autistic children and their parents in Ethiopia in general and the city in particular. Hence, it is delimited to parents who have a child enrolled at special schools/centers designed for children with autism.

Parents in this study are living in the capital city, Addis Ababa, and are closer to information, and have better access to the few services that are available in the country. Parents living in other cities and rural areas of the country where access to services such as special schools for children with autism is non-existent may have unique experiences. Simply put, undertaking a study in other geographical locations comprising different populations may perhaps generate different data and disparate implications for the services across the country.

Secondly, the cross-sectional nature of the study design could also be another limitation to the study. Our study was cross-sectional, meaning all variables/factors were measured simultaneously. Thus, the results cannot be causal but instead, are correlational or inferences regarding the direction of the relationships between variables. Thus, the conclusions are tentative at best. Despite a prediction and mediation model, it is difficult to determine which variable predicts the other over a period of time. A longitudinal investigation should be conducted to determine the predictive value of variables and to examine the journey that parents of children with ASD go through across different stages in their lives. This may contribute to the

understanding of the patterns of the challenges faced, and coping mechanisms used by the parents over a period of time.

Thirdly, although self-report measures are widely used in studies of children with ASD and their parents, the measures are susceptible to social desirability and recall bias. Since this study used self-report measures, participants may have answered the questions in a socially desirable way. Recalling information may also have been difficult; some of the interview questions asked the parent to reflect on experiences and feelings from many years back that might have influenced the accuracy of the information given by the respondents. To reduce these biases, the data were corroborated with other data sources, such as teachers in the centers, medical professionals, and founders of the centers to ensure the quality of obtained data. Finally, the availability of a limited number of researches in the Ethiopian context is also another limitation that influenced the literature on discussions and discourses of autism.

3.19. Summary of the Chapter

The philosophical foundation of the research rested on the pragmatist philosophy that advocates the inseparability of ontological and epistemological stances. The research processes focus on the experiences, behavior or action and test of the actors in a pragmatic context. Consequently, the researchers used a mixed research methodology and processes that combine philosophies, strategies, and designs. Exploratory sequential mixed method designs were used to address the objectives of the research. The deployment of a mixed method approach stems from the nature of the research question that coincides with the qualities, benefits, and strengths of applying the methods. Then, the data were collected and analyzed sequentially following exploratory sequential mixed method principles.

CHAPTER FOUR

4. Results of the Qualitative Data

4.1. Introduction

At this stage, the data were successfully collected through unstructured in-depth interviews and key informant interviews, which was relatively the most thorough process in the study. The interviews and field notes were transcribed. The transcripts were reviewed repeatedly in an attempt to find meaning and understanding through the themes. All phrases, sentence clusters, notes, and textual data were then reduced until vital themes became visible. Essential themes were made by considering phenomena unique to the parents of a child with autism and are fundamental to the overall shared descriptions and discourses of the study.

This chapter is organized based on the structure of themes that emerged from the qualitative data in line with the specific objectives of the study. Accordingly, themes related to lack of awareness, perceptions, and reactions of the parents to the diagnosis of autism, challenges, coping mechanisms, and supports for parents of a child with autism emerged. We present the participants' narratives about parenting a child with autism. Each narrative is supported by the participants' own words, directly quoted from the transcript. In synthesizing data from interviews, indentations were used to delineate the participants' verbatim answers. The participants' narratives are organized and compiled based on the identified thematic categories. Accordingly, socio-demographic characteristics of the parents who participated in the study, perceptions of parents about autism, challenges in relation to psychological, social, financial, coping mechanisms, and the supports are presented. The findings are presented based on the themes and research questions of the study.

4.2. Socio-demographic Characteristics of the Respondents

Table 1: Socio-demographic Characteristics of the Qualitative Participants

Parent Profile					Autistic Child Profile			Relation with the Child
Participants Number	Gender of the Parents	Age	Marital Status	Occupation	Age of the Child upon Diagnosis	Current Age of the Child	Gender of the Child	
#1	Female	38	Married	Trade (self-employed)	4	8	M	Mother
#2	Female	49	Widow	Petty trade	9	17	F	Mother
#3	Female	54	Married	Housewife	6	16	M	Mother
#4	Male	37	Married	Businessman (self-employed)	4	13	M	Father
#5	Male	61	Married	Pension	7	18	M	Father
#6	Female	44	Married	Housewife	8	15	F	Mother
#7	Female	33	Divorced	Government Employee	4	14	M	Mother
#8	Female	41	Married	NGO/Caregiver in one of the center	5	8	M	Mother
#9	Female	29	Single	Government Employee	6	10	F	Mother
#10	Male	46	Married	Non-Governmental Organization	3	17	M	Father
#11	Female	31	Married	Housewife	4	12	F	Mother
#12	Male	42	Married	Trade (Self-employed)	5	9	F	Father

N.B: M=represents, Male children with autism

F=represents, Female children with autism

As demonstrated in Table 1, participants for the qualitative study were 12 parents (eight mothers and four fathers) of children with ASD recruited based on the inclusion criteria. Their ages ranged from 29 to 61 years, with an average age of 42.8 years. The majority (9/12) of the participants was married, and three of the participants (each) are widowed, single, and divorced. All participants reported having only one child diagnosed with ASD. All the children of the participants received a diagnosis of ASD between the ages of 3 and 9 years. Of the 12 participants, four parents were employed in governmental and non-governmental organizations, three were unemployed housewives, two participants were leading their life by a petty trade and pension, and the remaining three parents were self-employed.

4.3. Challenges of Autism for Parents

“...you don’t know until you live it; thinking you know is different to knowing”

(Tessa, a 13-year-old autistic son; cited in Jack, 2016, p.79).

Narratives of parents raising a child with ASD revealed stories primarily consisting of different and numerous challenges. The respondents unanimously confirmed that nurturing children with ASD is complex and challenging. The following section presents these different dimensions of challenges or burdens experienced by parent participants of the study in relation to the psychological, social, and economic aspects that permeate throughout the shared stories.

4.3.1. Psychological Challenges

In this study, efforts were made to explore the psychological challenges of the parents. The parents spoke of the psychological challenges they are enduring while raising their children. Accordingly, lack of awareness, perceptions, reactions to the diagnosis of autism, and stress emerged as psychological burdens of raising a child with ASD.

4.3.1.1. Lack of Awareness, Perceptions, and Reactions to the Diagnoses of Autism

4.3.1.1.1. Lack of Awareness about Autism

As an emergent theme, the study begins with the results of the qualitative section with the awareness and perceptions of parents on the causes of autism before the diagnosis of their child with autism. Surprisingly, most of the parents did not know about autism before the diagnosis of their children. A third of the participants had never heard of ASD and only knew of it after their child was diagnosed. For example, parent #3, a mother of an autistic son had not heard about autism and was not aware of its characteristics: *‘before my child’s diagnoses, no... no, I can’t tell*

anything about autism.’ Similarly, parent #8 said, ‘I could say zero percent; when my son was diagnosed with autism, I had known about autism, before that, I had never known about what autism was.’

It was my first-time hearing about autism, I had no idea of what it meant. The doctor tried to explain the meaning of the disorder by saying, Yohannes will not easily interact with people, he likes to be alone, and he will not make eye contact with others. It was after that I began to educate myself about autism to understand the condition, its impact, and how to manage his behavior (Parent #7).

Three of the participants who did not have detailed information about autism had heard of it previously. These participants mentioned that although they had little information about autism before their child’s diagnosis and they might have heard the name, they had no deep knowledge regarding what it is. Parent #9 describes:

I didn’t know about autism, not at all, I knew the name, but I didn’t know what it was, for example, you might come across someone saying my child has autism or as a passerby you might see people with the problem but I didn’t know how it happens and its impact.

I had no deep knowledge about it. However, I had a hint; I used to hear the name and Joy Center for Autism once through TV. I only knew the name, far beyond that I had no deep knowledge and didn’t know what it was, the cause, care, and treatment options for the individuals or autistic children (Parent #4).

A key informant, a teacher from Joy Autism Center, also explained the lack of awareness:

Although the professionals in the center were working hard to reach parents, there is still a huge gap in awareness about the disorder among the public. People are recently coming to know a little about autism. Lack of prior knowledge and information about the situation would continue to make the children suffer from inhumane treatments such as tying the child to control the behavior, locking in a dark room, and isolation from the community. So, there is a lot to do on awareness-raising in the society.

Another key informant, a physician from Zewditu Memorial Hospital stated:

... Here, I could concisely and possibly say there is a low level of awareness of autism in Ethiopia. Most of the parents did not even hear the term autism, ever. Some who have heard the name will sometimes confuse with a mental health problem because of the symptoms, like a tantrum, aggressiveness, or over-staring... Some parents would come to the physicians late after the problem has got awful, horrifying, and even sometimes difficult for management. Do you know why? I said the awareness level is weak; attributing to the evil spirit, they would look for traditional herbalists or spiritual solutions. After all their way, taking too much time before the diagnosis, when they come to the hospital, the disorder would be severe and occasionally, inexorable. So, generally, there is a need to raise awareness and knowledge of autism in this country.

Based on the response of the parent participants and professional key informants, it is clear that there is a lack of awareness about autism among the general public including the parents. Some parents explained they had not heard of the term itself until the situation was happening and once again, most parents were unaware of the symptoms, and the possible treatments, care, and support for a child with autism.

4.3.1.1.2. Parents' Perceptions of the Etiology of Autism

Questions were asked to understand and comprehend participants' perceptions regarding the etiology of their children's developmental disorder. The participants gave different explanations regarding the etiology of ASD. Six out of 12 of the participants attributed the cause to supernatural power. Some of the parents thought it was bestowed by God to have a child with the disorder and they have accepted the situation because they have no choice. For instance:

Autism is a God-given gift. It is difficult to run away from God. I have acknowledged autism as a gift from God (Parent #8).

I think it was intended by God for me to have a child with autism because I didn't do anything wrong during pregnancy, in pre and postnatal periods. I did the same thing that I did to my other typically developing two children during pregnancy and after birth (Parent #1).

A few participants talked about the traditional ways of explaining a developmental disorder by mentioning curses or evil spirits as the cause and described going to religious centers for prayer and holy water in search of an appropriate cure for their child. Parent # 6, (a mother) specifically talked about her child with the developmental disorder as:

Different people tell me to check whether there is a curse from my side or his father's side, but only God knows. I think the cause is a curse or evil spirit, for this reason, I used to take him to the holy water and I still do that.

I did consider the illness as evil-eye and decide to take him to holy water and protestant churches for prayers. I believed that these were the options I can afford at that time. However, I haven't seen any change (Parent #2).

Study participants had different levels of understanding about autism. Few participants perceived autism as a life incident or event that can happen to anyone and understood that the exact cause is not yet known by the scientists in the field. For parent #5:

Autism is a situation or incident that will happen to anyone without considering ethnicity, gender, or economic class. Regarding the cause, people say many things (attributing to supernatural power) but it is not exactly known. It is not even identified by doctors and scientists in the field. But the genetic makeup or environmental causes could be mentioned. Here, not even knowing the reason makes you to question everything (why this happens?) are there any mistakes made during the pregnancy by my wife? Did I do any wrong things to people in the past or what? –was frustrating until you start accepting the situation.

Most of the participants have no clear understanding of the causes of autism. Some of them continue to attribute the cause to supernatural power, others traditional, with very few alleging scientific explanations. There are many controversial arguments about the etiology of autism even in science. According to scientists in the field, different genetic and environmental factors are responsible for autism. As stated in a literature review, the exact reason for a specific cause is still unidentified and not known (NIMH, 2011). Some of the parents' misconceptions about the causes of autism are partly due to a lack of awareness or because of the inability of science to identify the specific, exact cause for autism in their child, which may create stress for participants in thinking about and questioning the causes in their child's case.

4.3.1.1.3. Parents' Reactions to the Diagnosis of Autism

"I was shocked and felt lost" (Parent #11).

Participants reacted to the diagnosis of autism in a variety of ways. The diagnosis processes for the majority of the parents were very long, labyrinthine, and complicated procedures. The majority of the parents demonstrated a range of emotions immediately following the diagnosis, of which the salient feelings and reactions were shock, confusion, denial, despair, and sorrow, feelings of blame and guilt, and being overwhelmed by the news. However, other parents reacted with feelings of relief and described it as a learning session to start a new chapter in their life's journey.

Most parents spoke about the time they heard the diagnosis as a very shocking, despairing, and disturbing experience. Parent #6, on hearing the diagnosis, did not want to believe what she heard about her child and reacted with shock, confrontation, denial, and outcry. She articulates [with saddened and lower tone of voice]:

... It was a hard time when I heard that my son had been diagnosed with autism, [clearing tears from eyes], I did not want to believe, I confronted the doctor because I know other children with [low functioning] autism and that is not how they behave. I just wasn't prepared to accept it. I was in a denial for a while. I knew what autism was in general, but I didn't know its types.

... Really, I was shocked and felt lost when we received the diagnosis, I felt like a person who had lost everything... especially after browsing the internet about autism, I stayed home the whole day and I was just in tears literally for the first two days. I'm crying, wondering how I am going to get through this. Why me? What did I do wrong? I couldn't stop crying and it was a devastating experience (Parent #11).

When the diagnosis was formally confirmed by the physician, parent #7 (a mother) described how she felt and reacted by saying,

I was shocked very much... When I first heard that my son was suffering from a disorder that would last for the rest of his life, I have out-cried a lot. I was very disturbed and didn't even know what to say. The shock and the pain are something you can't explain in words... Especially if it is something you never heard in life, autism, happening to your child, I mean it is hard. I can't tell and express how exactly I felt. I was sick for the whole night, thinking about the incurability of the disorder and the future life of my child.

The initial reactions of (parent #3) to the diagnosis of her son with autism included stress, feelings of blame, and guilt. She asserted:

When they [the medical professionals] tell you, it comes as a bit of a blow, oh my God! I was just a wreck; because we knew nothing about it, you know, you think the worst, like what am I going to do? How do I care for him within our limited resources? It generally blows your mind. As a result, I felt stressed and cried a lot for some time...what makes me feel bad is I took the blame and guilt to myself. You know, during my pregnancy, I worried a lot because of the bad relationship between my husband and me. He used to be a drunker, alcoholic (which he has stopped after our child's diagnosis). He drinks almost every day, we run out of money very early each month, I would cry, stressed a lot and I

don't provide appropriate care for myself and the child in my womb (I don't eat well and take good rest). Thinking about my stress and lack of good care during the pregnancy, I feel guilty and blame myself. I thought I would not have a child with autism or it might not happen if I would take good care. ... I was distraught, heartbroken, and it was like the worst feeling...

A key informant from Zewditu Memorial Hospital also stated,

When the parents come to health facilities and are told it is autism, most of them would not easily understand the disorder or very few would understand. However, regardless of their level of understanding, their level of psychological preparedness to accept the diagnosis result and planning on how to deal with the result is very questionable. Most of the parents react with tears, sorrow, shock, and despair... you might see rarely, individuals accepting the situation.

...Upon the diagnosis, some feel blame and guilt, shock or denial. ...One key factor for the negative reactions might be due to a low level of awareness and the prevailing belief that it is a result of God's punishment for one's wrongdoings, which may in turn, result in a feeling of self-blame, guilt, and stigma. Only very few (those who were fed up with the diagnostic process or suspicious of the disorder) accept and endeavor to learn how to live with the challenge and help their children (A key informant from Nehemiah Autism Center).

In contrast to the other participants who felt great concern about their child's condition, a few were relieved to get the diagnosis, knowing what was wrong with their child after an infuriating process. Parent #5, a father, stated,

When we found out what was wrong with Daniel, we (as a parent), felt relieved. Now things were clear. Before the diagnosis, we faced obvious, more pronounced and great impact to know what was wrong with our child. We have been at different medical centers; none of them came up with a diagnosis of autism. As we didn't get a response from the medical aspect, we visited numerous religious places for holy water treatment. In all our effort after a long period, numerous ups and downs, a physician at a private

medical hospital diagnosed our son with autism. Then, we felt relieved, our child is autistic; he is a child who needed to be disciplined, exceptionally cared, and needs to access a special school.

Parent #8, a mother sharing a similar experience, also felt a bit of relief on receiving her son's diagnosis.

When Yafet was finally diagnosed, I felt a bit relieved because whatever my son was going through had a name. I had known what is wrong with my son, and I knew what I was dealing with. I decided not to give away my feelings; all I cared about was how I was going to help my son, what I could do for him because I have spent and drained a lot to know the problem [autism]. Then, started working on how to handle and help him. I made things up in this way.

Almost all the participants had no prior experience with ASD. Some of the parents felt confusion at the very beginning when they could neither identify nor handle their child's odd behaviors and expressions. They only gained more knowledge or awareness about autism after their child had been diagnosed by the professionals. Immediately after the diagnosis, parents had a range of reactions including stress, shock, denial, and feelings of guilt, blame, sorrow, and grief. Only a few participants were relieved by the fact that their confusion was over and knowing their challenge had a name, autism. Overall, although the negative feelings and reactions were dominant, a few parents who felt relieved perhaps reframed their mind early to thinking towards helping and providing care and support to their children.

4.3.1.2. Stress

The participants expressed that they experienced a high level of stress and disturbance due to the burdens associated with raising a child with ASD. The majority of study participants experienced stress, deep sadness, worry, and grief in caring for a child with autism. Accordingly, parent #5 described his experience by saying:

The psychological impact of caring for an autistic child is vital. Emotionally and physically, my wife and I have experienced stress and we were in a burn-out due to caring for our child with autism. I am more physically tired, I became exhausted very quickly. When I am at work, it is difficult for me to focus and function efficiently, as my body feels tired more than before. My wife was always worried about our [autistic] son. She feels frustrated, distress, and gets offended easily.

The parents also reported stress during their day-to-day lives and in thinking about the future. Therefore, the sub-themes identified under this theme were explained in four parts: stress during diagnosis, stress from the busy day-to-day routine (schedule), stresses from managing the behavior of the child, and stress about the future.

A. Stress during the Diagnosis

Most of the participants experienced a high level of stress during the diagnosis of their children with autism, which began from the time they first knew about their children's health status. Before acceptance, the participants went through denial, shock, and grief. They expressed the moment of learning the diagnosis as the most heartbreaking incident in their lives. One participant (parent #2) remembers it as follows:

When the doctor told me that my daughter is autistic, I had no clue about what autism was. After he explained it to me, I did not want to accept that my only child is autistic. I

felt that the whole world, even God, has turned his back on me. I was so stressed that I closed my door and stopped my relationship with everyone for a week.

Parents gave different explanations for their first emotional reactions. Parent #9 mentioned it as:

It was the most painful thing I have experienced, she is my only daughter, and knowing she is autistic was devastating. Everything was blocked for me; I cried a lot that day.

All participants conveyed that although they are less stressed than at the time of diagnosis, they still experience stress when they think about having a child living with a disability and the caregiving responsibility. Participant #5 described the stress that emerged from thinking about having a disabled child,

I am adapted to this life but it does not mean that I am okay with it. It has a stress. I am jealous of parents who have 'normal' kids that would go to the toilet by themselves.

Regarding the initial reaction of the parents, the participants mentioned the incidence of autism as a major life stressor and that they experienced shock, confusion, denial, and self-blaming. Some parents in this study also related the cause of autism with the cultural attitudes of associating the disorder with their prior wrongdoings (sins), evil spirits, and punishment by the divine or supernatural power.

B. Stress from a Busy Day-to-Day Routine (Schedule)

Respondents confirmed that nurturing children with ASD is challenging and extremely demanding. The daily schedules for most of the respondents entailed feeding, getting their children dressed for school, taking them to school, going to work, picking up their children from school, and taking them to their various medical treatments. Parents reported that their daily activities were very routine and scheduled. In this regard, parent#5 expressed his situation as:

...My life is busy, tedious, and hectic but organized. From the time he is awake to his bedtime, he is the main focus, as I hope that he is safe and well taken care of. It makes you busy and very scheduled. If I did not follow the schedule, my child could not function. That caused more stress. I can say, every day except for the weekends (where my child will not go to the centers), I have to follow the very busy daily routine.

I left almost everything else. Sometimes, I spend the whole day busy without a rest running around my child to control him (especially on the weekends where he didn't go to the center) if he is having a bad day and meltdowns. I am paying a lot of sacrifices and it is really a great burden (Parent #7).

Some mothers illustrated another aspect of the challenge related to their children with autism, whereby they could not pay proper attention to their husband and the remaining children without disabilities. They have been urged to give more time to take care of their children with autism. Participant #7 told the researchers how hard it is to have a child with autism because it takes a huge amount of time to care for the child, which makes it difficult to have time for herself, her husband and the two typically developing children. As she explains:

He requires most of my time. I give a mammoth amount of my time to my son. As a mother, you have a lot of responsibilities, and it makes the burden of being a mother even more difficult. Generally, I have no time to myself, to attend social events, and I feel very busy. Let alone caring for myself, I don't think I have given proper care for my husband and the two other children without disabilities as I plan everything around my autistic child.

The participants had a strong fear that due to their strange behavior, their children with autism might have been abused by home servants and even the siblings at home and members of the local communities including their peers without disabilities. Among the study participants, two mothers were forced to leave their job and stay at home with an intention to take care of their respective child with autism. They further reported that this situation isolated them from

engagement in community life and work, which adversely affected their interpersonal/social interactions and incomes.

Generally, a majority of the participants were required to protect their children with autism, which forced them to have tight schedules and go through hectic life being overburdened by extra responsibilities and duties they needed to carry out for the sake of the safety of their child with autism. The participants further depicted a situation in which they were always in a state of stress and fear due to the inability of their children with autism to respond properly to their environments. Participants found daily activities cumbersome, indicating that it affects their day-to-day life, as everything has to be on a schedule and routine. Although the day-to-day experiences were challenging, the participants became more involved in their children's lives and gave due emphasis to their roles as primary caregivers.

C. Stress from Managing the Behavior of a Child with Autism

The most challenging aspect associated with ASD was when their child became upset, sometimes leading to violent behavior. Unpredictable behavior is especially challenging for parents and threatens their ability to function well in a consistent mode. Parent #12 said, "*My child has difficulty in following instructions consistently. ...if she thinks that she has a better option, she doesn't remember and is guided by it.*" Most of the parents shared that managing their children's behaviors can often be challenging and stressful. For example, parent #6 explained the volatile behavior and quick temper as:

Her unpredictable behavior is I can say challenging for me. I feel frustrated when I told her to do something and she does the opposite. ...Though it occurs once in a blue moon, the difficult behavior of my child is she'd get very angry, screams, shout, and slams the door. ...She is smart but when she has a meltdown, it's overwhelming for her and me. She

become almost frighteningly angry very quickly, which is weird and you couldn't manage easily.

Parents #9 said her daughter would become exceedingly frustrated especially when she gets upset, which would make her think and feel bad. She described the distressing incidents:

When my child thinks things are done against her interest or feels threatened, she would be –upset and respond by screaming, banging against windows or walls, hurting her arms, biting herself, disturbing, throwing everything around her. Sometimes, she would be punching, kicking, and bailing up with me. It would be a nightmare that feels bad.

Dealing with the anger or inflexibility of the children was stressful for some parents and challenged their patience and relationships. Parent #8 portrayed:

Yeah, he is facing a big meltdown. He is quite polite, he has got quite an engaging personality but if he was aroused and starts to have a meltdown, he will lash out by yelling, hurting, and biting himself. He would also break things, throw things, hit, punch, and kick even other children in the center. That is appalling for us [as a parent], something that can challenge your patience, and rarely I even hit him, out of grievance and anger.

...My child does not consider my need. Occasionally, he might ask the same question repeatedly while I want to talk to my friend or want to see an interesting movie; he asks very simple questions that he knows the answers to; he just wanted it again and again for not less than 20 or 30 minutes. Then I found it demanding and run out of patience in these kinds of situations (Parent #7).

After analyzing the narratives, it became evident that the parents described that their children almost having a dual nature and character. They can be upset either after a long or short calm. Participants reported that their child's mood changes can be accompanied by physically aggressive behaviors, including pushing, hitting, kicking, or throwing items. Therefore, their

child's self-regulation problems, both in and outside of the home, caused considerable stress and worry in conjunction with significant management challenges for parents during these occasions.

D. Stress about the Future

The parents viewed and described the future as challenging and stressful. The participants shared unpleasant thoughts that are in the back of their minds about the future regarding their children and themselves. Both are viewed separately as, *stress about the future of a child with autism (i.e., concern about the child's future)* and *stress about the future of the parents*.

i. Stress about the future of a Child with Autism

The parents' worry about the future of their children in terms of who cares for their children when they can no longer be available for them, and what the future holds for their children appeared to be a major cause of concern. For example, parent #3 worries about what the child is going to face in the future and how his life would turn out if something bad happened to her because most of the things that the child needs are tied to her.

My child's future is the main thing that worries and stresses me a lot. What concerns me about the future of my child is who takes care of my child if I will die or something happens to me? Because if bad things happen to me, I thought how my son would be? I am the one who understands his behavior; he needs me to wear clothes, eat, toileting, socialization, and depends on me for survival basics in general. ...Sadly, [with tears in her eyes], I wish if he dies either before me. I think this is weird, but due to his situation, I don't want him to suffer. I don't think he will have someone to help and manage him like me...

ii. Stress about the future of the Parents

Some of the participants were stressed about their well-being and ability to deal with their children in the future. Participant #6 expressed her distress about herself that stems from caring for the child, her future ability to care for her child, and thinking about the future of her child:

As my child grew up, the burden of caring for her is making me thinner and thinner; I am looking old more than my age, and my friends, due to the distress. Because I gave everything to my child and I don't take care of myself and my lifestyle. ... her survival depends on me, and if unexpected life events such as death or serious health problem could hamper me from providing proper care, who would take care of my daughter?—is the question that stresses me a lot. Of course, I am asking and praying to my God to give me full health until I see the end of her life.

Generally, stress experienced by parents of children with autism in different spheres of life seems to be a major psychological challenge. On the contrary, three participants stated that they are very hopeful and that they fear nothing when they think about the future. These parents mentioned that believing in God, looking at the behavior, and seeing the changes in their children have made them feel better and hopeful about the future of their children. Although most of the participants discussed their fear about their child's future, parent #8 (a mother) talks about the future in a very optimistic way: *"I don't think I have to worry much. Who created him in the first place, God, and I do not doubt that he is going to live a better life. I think he is going to be okay. He is friendly and he can live with anybody. ...If he can work and support himself that is enough for me."* Parent #1 also stated, *"I don't fear the future and nothing worries me, our God who created him knows and has the way for him. I hope that one day he will survive on his own as everybody does."*

4.3.2. The Social Challenges (of Raising a Child with Autism)

The challenge of raising an autistic child has implications for one's social life. The degree of participation in social life varied from one participant to the other. Very few participants were actively engaging and experiencing no visible social impact. For the majority of parents in this study, caring for a child diagnosed with autism has restricted their participation in social life. Thus, the shared experiences and results provided interesting insights into the main social challenges faced by parents of a child with autism. The parents spoke of the social challenges organized under the themes: interpersonal loss and controlled social life, negative reactions from the public and stigma, and challenges in marital and sibling relationships.

4.3.2.1. Interpersonal Loss and Controlled Social Life

Of the social challenges discussed by the participants, the first subtheme was interpersonal loss and controlled social life. Throughout the interviews, participants spoke of a variety of ways in which their social experiences were limited by being a parent of a child with ASD. Some participants indicated that one of the social challenges that ASD had twisted in their life is the loss of significant relationships resulting in social isolation. For example, parent #1 lost friends and perhaps some of her relatives:

The social impact of autism is not easy; as for me, it makes my life tedious, you know, I have lost some of my friends or important relatives. Caring for a child with autism makes your daily schedule very, very busy. Socially, a lot of people don't understand that. ...If there is no one in the house to care for your child, you will not attend social events and ceremonies freely. Then, they will separate their ways and no one wants your friendship to avoid the social dysfunction and glitch. Here, you may feel isolated, you will not hear about the social occurrences, and at the same time, you lose your interpersonal or significant relationships with relatives, neighbors, and friends.

Controlled social life was another challenge for the participants. Some asserted that being a part of social life by attending social gatherings and events such as wedding ceremonies, birthdays, get-togethers, and other cultural celebrations were altered. For others, though their social life has changed, it did not turn unmanageable. For instance, parent #9, a single mother described the challenges as:

...My social life is affected badly; I can say I have no liberty to attend social gatherings such as weddings or birthdays. It's either there has to be an adult guardian with her or I will not go to that place. ...look, going with her is impossible; when she sees a large number of people, she cries and becomes very disturbed. Usually, I will be back off or I do not participate that much preferring to remain at home with my child. However, rarely, I will leave my daughter to my neighbors and come back home early thinking about her behavior.

Our social life is affected but somehow we are managing. In the absence of someone, one of us goes to the event and one of us stays home (parent # 12, a father).

A key informant from Joy Autism Center described the controlled social life among the parents of a child with autism as:

You know how social gatherings such as weddings and birthdays are valued in our culture and society. But mostly, parents of a child with autism will stay back or entirely halt attending social events and different ceremonies. You know, these children require a lot from their parents and most of all, their time. In most cases, let alone attending social events, you may see a mother quitting a job to stay with her child. If one does not take care of these children, it is difficult to go out and become involved in social events. Hence, social life is challenging for these parents. ...usually, their daily routines are consistent. Sometimes, parents isolate themselves from public places and do not want to mix with people. This deprivation or controlled social life is partly due to fear of societal attitudes or to keep the interest of their child.

Generally, as a social challenge of raising a child with autism, some parents have faced interpersonal loss (isolation from relatives, neighbors, and friends) and a controlled (restricted) social life. These effects on the social relationships of the parents were the result of lack of or much more restricted involvement in social activities like visiting relatives, friends and sick people, attending burials or wedding ceremonies, and going to church. Parents were unable to leave their children at home alone thinking that they might hurt themselves or their siblings because of tantrums, aggressive behaviors, and/or the dysfunctions associated with the disorder.

4.3.2.2. Reactions of the Public and Social Stigma

The second subtheme identified under social challenges was reactions of the public and social stigma. In their daily lives with their children on the spectrum, participants faced negative reactions of various people including neighbors and the general public. The participants reported differing views on the reactions and comments by society. Accordingly, parent #4, a father, reported sympathy and love from neighbors and community members:

...Everybody is sympathetic toward my son. People around me, especially, my neighbors love him and they take good care of him when his mother and I were not around. We are lucky to have these kinds of neighbors. ...you know people around me know my son's condition even if they don't have detailed information and knowledge about the disorder. They are showing countless sympathy for our son and encourage us when they see little progress on our child that motivates us to provide more care and treatment for our child.

However, most have talked about negative reactions and perceptions of society and how that bothers and distresses them. The lack of understanding from the public or the way people react when they see their children and judgments was described as a hard time, which makes them feel sad. As parent #9 describes:

Autism is not well understood by the public in this country. Society mostly perceives these [autistic] children as being raised (socialized) in a bad manner. Mostly, I see people's eyes on us, feel judging us, I mean, everybody stares at her or stares at us. I did feel nobody seems to understand why she displays such unique behavior and what I am going all the way through because she doesn't seem disabled. I get angry when a person tells me what I should be doing to make her behave well.

...people thought he was just a boy socialized in a bad way, not knowing he is autistic is what makes them judge and think that way. As a passerby, while individuals occasionally see his tantrums, aggressiveness, and screams, they would come to me and tell me how to make him a calm and unspoiled child. ...when I tell them he is autistic, they suck on lips for me, which makes me feel bad (Parent #7).

The community is not aware of children with autism or other mental illnesses. They consider them as the children with a bad omen, having a curse or being punished for a prior sin. It is distressing for parents like us. I am a protestant married to a non-believer; my sister told me that some of my relatives thought as if it is the result of punishment from God for this sin. It makes me feel sad. ...the other thing is when you move with your child in public places, the way people react and stare at you just makes you feel different and pity. I wish people had the awareness and saw it as an ordinary incident. I hope they can just see them [autistic children] like a typical child (Parent #3).

Social Stigma: Another key subtheme identified as a social challenge for parents of a child with an ASD was indeed 'social stigma.' Stigma as mentioned by parents comes from friends, neighbors, relatives, and the general public. Even though the extent and source of stigma varies, the parents reported rejection/avoidance, blaming looks, rumors, fisting, pointing fingers, staring, and non-verbal cues as indicators of stigma. Rejection is one way that the parents feel stigmatized and discriminated against. The parents have observed rejection of their children and of other family members. This rejection is manifested in different forms such as by not responding well when they need assistance especially when the child disturbs, not coming to

their home, lack of interest in inviting them home, and by pushing away (distancing) the child or parents. For example, parent #6 feels rejections from her friends and describes the situation as:

I have noticed my friends are becoming fewer and fewer, I have lost friends on the way. When you ask them, their reason was 'I don't think you have time to chat and spend with us.'

...I have also observed some of my relatives especially from my partner's side would not have good eye contact with me, thinking as if I am the cause and reason. Because of the history of mental health problems in my family (you know, my uncle has a mental health problem) (Parent #8).

Though half of the participants mentioned that their neighbors are sympathetic towards them, two parents spoke of how neighbors' lack of understanding stigmatizes their child:

Some neighbors didn't want their children to play with him as if his condition is a communicable illness (Parent #5).

Some people won't let their children come to your house; they don't want their children to mix with my son thinking he is possessed by evil. So they want to stay away from you as much as they can. It was an embarrassing experience...(Parent #7).

Some experience stigmatization that often placed the parent in a position of 'blame' without considering their reality. In this regard, parent #3 spoke about the stigmatization in the form of 'pointed fingers, blaming looks, and staring' whenever she is out in public with her autistic child:

When you go out in public places, you may come across pointing fingers, unusual staring, or a blaming look. They see me as the woman with a badly behaved child, as if it is my fault, or they see my son as naughty, without knowing that he is challenged, which makes me feel bad and these are the sort of social challenges that I am facing.

The participants' explanation of why people stigmatize and discriminate against them was lack of awareness by the community such as associating the illness with evil, thinking that the children are aggressive, and considering the behavior as deliberate. Parents also mentioned that there was a situation in which people relate it with parental sin and as if it is the result of God's punishment. However, three parents did not face stigma for various reasons including having their own house with a separate fence, their children's behavior was not aggressive, or they have supportive neighbors and understandings relatives.

4.3.2.3. Challenges (of Autism) on Marital Relationships

As a result of having a child diagnosed with autism, some of the participants raised marital discord as an issue. For the rest of the parents, rather than affecting their marital relationship, autism has strengthened cooperation in taking responsibility and sharing life burdens. Consequently, autism had little or no impact on their marital relationships. Hence, the marital relationship was found to be affected both positively and negatively. Parent #4 described the positive experience after their child's diagnosis:

I think there's some good to it in the sense that, after the diagnosis of our child with autism, the relationship between my wife and me became even enhanced. I support her when she becomes tired and she does the same. She is an amazing wife and I am also more attentive to her and our child than before [the diagnosis]. I don't think it has negatively affected our relationship.

For other participants, the diagnosis of their child has brought difficulties to their marital relationship. Some parents spoke of disagreements between the spouses when stress levels rose too high. For instance, parent #11 illustrated the negative experience:

The birth of my daughter with autism as I said earlier has brought a lot of challenges. It has created stress in our relationship because there were also lots of arguments and

disagreements between my husband and me. Her father is not attentive and caring toward his child in domestic chores, schooling, medication, and therapies. He has no more than a breadwinning role, which is not even that much sufficient. Of course, I have stopped working (my salaried job) right after the diagnosis of our child and sacrificed a lot. It was just me who is responsible to care for the three children including the autistic one. I am the one to manage the behavior of our child, to feed, clothe, pick from school, make follow-ups on medication and therapies. It was exhausting. Look, when I am overwhelmed, stressed, and frustrated, I will shout and yawn at my husband. We are continuously arguing but he is not changing. ... I could say autism has affected a lot on my personal and marital life.

Generally, though some parents claimed autism has enhanced their parenting and has no or little effect on the quality of their marital relationships, others asserted autism has exerted a formidable toil on parents' marital relationship by placing additional burdens of managing parental life and their day-to-day functioning.

4.3.2.4. Challenges of Autism on the Siblings (from the parents' perspective)

Raising a child with autism places some extraordinary demands on parents and the family members like siblings. For the research participants who had other children, a majority of the participants had positive experiences. The siblings were very welcoming and understanding of their brother/sister with autism to the extent of changing their career interests to help other autistic children. For example, parent #1 stated, *“My other son is a defender to my child who is autistic, aspires to increase advocacy in Ethiopia by opening a special school for autistic children to help other children with autism. He also helps in teaching skills and socializing especially on how to eat and wear clothes.”* Unlike this case, other participants reported that having a child with autism negatively affected the other siblings in their household. Most of the participants mentioned that they are unable to give enough time and care to their other children due to providing extra care to the special needs child. Parent #11, a desperate mother, portrayed her typical children who feel less time, care and treatment provided. She shared the embarrassing and upsetting experiences as:

...Of course, yes, it has no question. I am giving most of my time and attention to Winta than her elder two sisters. When she fights them on their toys or properties, I would say please give her and go away! Occasionally, her immediate elder sister asks me, am I not your daughter? You are always in favor of her and telling me to leave everything for her. ...she is also not comfortable going to public places with Winta (autistic child) because she sometimes screams, throws food or has tantrums. It was too embarrassing for her sister when she sees people laugh or staring. She sporadically feels thwarted, upset, and distressed.

This example illustrated the interplay of concurrent challenges for the siblings and parents. The child's meltdowns in public caused embarrassment for the sibling and at the same time, the parent also obsessed about the typical child due to giving less time, care, and treatment.

To sum up, the participants raised and discussed interpersonal loss, isolation and restricted social life, negative reactions of the public, and stigma. In addition, challenges on marital relationships, and siblings were also asserted as the social challenges of raising a child with autism.

4.3.3. Financial Challenges of Raising a Child with Autism

Financial challenges are another major theme that parents articulated as a constraint in their lives. All the participants agreed that caring for a child with ASD requires extra cost, attention, and effort. Hence, caring for autistic children has its own economic consequence. Financial challenges were commonly mentioned by most of the participants. In their caregiving process, parents incurred different kinds of financial expenses. Some of the participants complained about the financial burden associated with the cost of providing everyday basic needs (such as the high cost of food, clothing, and transportation costs). For instance, parent #5 and #8 described the extra expense as:

Caring for the child requires extra expense. You need to provide a balanced diet. Unfortunately, he chooses certain types of food, for example, he likes cooked beef. The cost of buying a slice of meat is very high in which we are unable to afford due to our financial burden. I am also unable to afford the clothes, materials for the child's hygiene, and transportation costs for me and the child (Parent #5).

Having a child with autism plus the transportation cost for medical treatment or therapies and the increasing cost of food is the main financial burden for our family. ...We are using public transport. But it is not convenient for him, sometimes he cries and his tantrums would come when a lot of people are gathered on public transport. Managing his behavior in this situation is difficult. Let alone using a private taxi, using a minibus taxi is of high cost for me. I think the financial constraint is much stronger even than the emotional or social one for me (Parent #8).

Two participants had resigned from their jobs to provide full attention and devote time to care for their child with ASD. Quitting a job has forced them to become a housewife which in turn affected the parents' income in being able to provide better care and treatment for their child. In this regard, parent #6 explained:

I did quit my job just to take care of my child. I used to be a cleaner in a private company. I have stopped working and became a housewife believing my child requires more attention and care. Now, we are living by my husband's monthly income. Autism has affected a lot on my employment, income, and work.

Others raised the issues of medical costs and extracurricular services (like speech therapy) the child needed. For example, parent #2 shared:

I have spent all my money on medical services and buying medicines for my child. I am leading my life by petty trade. The money I am making is not sufficient for more than paying for the house rent and our food. If I had money, I would look for better care and treatment for my child. Now I can't afford it and my only option is praying to God to improve my child's situation.

Two participants identified spending large sums of money on the services and treatment of their children.

Umm, in terms of finance, although we did not have many financial challenges, caring for an autistic child is like an investment venture that requires a huge amount of money. It is not easy; [with long out-breath] we have spent a great amount of money on medical services, medicines, special foods (like imported gluten-free diets), therapies, toys, and school supplies. It makes our finances tight. But still, thanks to God, because we have afforded (Parent #1).

According to the key informant from Joy Autism Center, autism adds pressure on parents' expenses and contributes to financial constraints and difficulty:

When poverty is attached to autism, it is really difficult and devastating for the parent. A child with autism requires more time, energy, and money than a typical child. The parent falls in the paradox of making a living to survive and at the same time, they were plagued by providing care and support for their autistic children. Sometimes, the mothers would leave their job and employment and rely on their husband's income to provide better care. ...financially, it would also add pressure by requiring additional expenses for feeding, medication, transport, specialized toys, and services. Fulfilling all these needs, especially for a single and destitute parent, is appalling and overwhelming.

Finally, autism has created a financial challenge and pressure on the participants, meaning, almost all the parents claimed an imbalance between what they are earning and what the child's needs demand that creates stress in their homes and lives. The children require more care, effort, and money to teach them skills at home. Hence, the parents need space, toys, and time. Nonetheless, almost all the parents with financial constraints are not living in their own home and usually rent a small affordable house in a compound where other people live. They are also in need of a space to socialize their children in addition to the financial challenges they are facing.

4.4. Coping Mechanisms

Parenting is not an easy process for parents of a child with autism. The parents have passed through several psychological, social, and financial challenges. In an attempt to adapt and cope with the challenges, parents have used different coping mechanisms. The strategies could be categorized into 'positive' and 'negative' coping mechanisms.

4.4.1. Positive Coping Mechanisms

In an attempt to help the children and manage the challenges, participants were asked to share personal strengths and helpful coping mechanisms. According to Walsh (2003, 2006), positive coping responses and adaptation to adversity utilizing strengths contribute to the process of building resilience. Hence, parents shared several strategies they attempted to change or modify their situations. Overall, six key strategies were identified under parents' positive coping mechanisms: coping through religion, acceptance, reframing/meaning-making, advocacy, patience and perseverance, and seeking social supports.

4.4.1.1. Coping through Religion

Religion was the most reported coping mechanism that helped the parents to cope with the challenges. 'Belief in God' as a strategy to cope with the stress was evident in the narratives of most parents. One participant (parent #2) identified her strong religious beliefs and specifically her belief that *"God does not give you anything more than what you can handle"* as a source of resilience. Almost all participants described their hope and faith in God, expecting to see improvement in their child. For instance, parent #7 finds relief in thinking of the power of God. *"I believe my God is Elshaday (omnipotent). With God's willing...I have great hope in God to see him changed."*

I believe no one is created without purpose. Who created him? I know it might not give a sense to others, but with God's grace, he will get better and I am also seeing changes from time to time. In the future, I believe God will make him fine (Parent #3).

Some parents described specific activities they perform within the religion. They engaged in spiritual beliefs and used spiritual healing methods such as holy water and prayer to their

children (to lessen the developmental problems) and themselves (to cope with the challenges they faced). For parent #1:

I am coping better because of God's help, who walked with me throughout my journey of caring for this child. I am praying, drinking holy water, and letting my son drink the holy water too. God is also answering my prayer. My son's tantrum is reducing; he is also sleeping more hours and my stress is becoming lesser and lesser. ...I am praying on daily basis, usually after I wake up from my sleep that has helped me a lot to cope.

The majority of parents repeated how they rely on God and use their religion as the main strategy to alleviate their distress. Some portrayed feeling better when they would go to church to attend religious ceremonies and worships. Parent #11 indicated:

I go to church with my daughter to attend church programs. I would go with her because I want her to be blessed. ...occasionally religious men in the church would pray for us. When I feel sorrow and overstretched by the challenges, I would go to church to pray, worship, and attend religious ceremonies. Through praying, telling my problems to God, I would come back home getting inner peace and feeling better.

... Far beyond worshipping, reading the bible, praying, and improving my spiritual connection with church brothers and sisters, especially whenever things get hard, I go for counseling in church and talk to my friends there. They will give you advice and suggestions which help me to have emotional well-being and to keep on [just being resilient] (Parent#3).

Coping through religion has helped some parents to accept their child's diagnosis of autism. For instance, parent #2 asserted, "...of course, I have accepted autism believing she is a gift from God and God will care for his every creature." Therefore, the statements from parents manifested the importance of their religion as a resource to cope with their challenges and stresses.

4.4.1.2. Coping through Acceptance of the Situation

I think acceptance is critical. The main step towards caring for a child affected by autism is accepting the situation. If parents are in denial for a longer time, it will lead to frustration but those who can accept it early can find ways on how to train and teach their children (A key informant, a medical doctor from Zewditu Memorial Hospital).

The above key informant explained the importance of acceptance in preparing parents to support their child at home. Similarly, some participants also mentioned acceptance had led them to comprehend the situation of their child. This was found to be an important step in caring for a child living with autism. As noted by a key informant from the staff of Joy Autism Center, and parent #8, if one can learn how to accept the situation, it is less challenging to stand against the stressors that come along the continuum of helping the child. For instance, a key informant (a therapist) from Joy Autism Center stated:

If parents can accept autism shortly, the process of overcoming the psychological challenge is easily bypassed. I see acceptance as more important than other factors. It simplifies life for the child, parents, and even for us in working with them.

... Conversely, when parents are unable to accept the situation, it will not be helpful for the children and the parents. As for me, acceptance is vital, essential, and necessary. If you accept it early, you will move on to find the key. It is a key to the challenges that come along with the process of raising a child. Immediately after the diagnosis, I think, the professionals in the field have to immensely focus and work on helping the parents to accept the situation (Parent #8).

Another key informant from Nehemiah Autism Center also added voice to the relevance of acceptance by mentioning how they provide parents training and counseling to help them accept the situation and provide help to their children.

...we are working with parents to avoid the anger, frustration, feeling of “why me?” and denial, of course, as you know, it will not come overnight. To work towards the progress of the child, first parents should be able to accept the situation of their children.

Some parents spoke of the tension and long time it took to accept and adapt to the diagnosis. For parent #3,

In the beginning, my husband and I were confused. Your life is not what you necessarily anticipated or planned it to be; it is full of ups and downs. It took almost two years to get there. Of course, it is a process. But as time passed, and learning it isn't going to go away, we just come to accept it. Now I think acceptance of ASD is the integral part that helped me to better overcome the difficulties of parenting a child with ASD.

Some, nevertheless, immediately accepted the situation and decided what they could do. For example, parent #10 stated:

Immediately after the diagnosis, or once I have realized the situation is not going to change, I haven't spent much thinking about the negative impacts of ASD on my child and the family. Rather, what I got to do is accepting the situation and thinking how best I could help my child. Then, I decided to put all our effort into providing care and fulfilling the needs of our child. I have managed it shortly and started supporting at my level best.

Generally, as a resource or coping mechanism discussed by parents and the key informants (the professionals, staff, and owners of the organization), accepting the situation plays an important role in strengthening parents raising a child with autism. Acceptance was explained as the vital step towards the solution. The duration of time until the parent accepts the situation differs from one parent to the other. The key informants enlightened that those parents who accepted the situation early have usually improved understanding about the situation of the child, provide support and work towards a solution for their child, and are better to overcome the challenges of parenting a child with ASD.

4.4.1.3. Coping through Reframing

Some parents described positive reinterpretation (reframing) of the situation as influencing their abilities to manage burdens and the subsequent stresses in their lives. Beyond helping to manage and make sense of the challenges, reframing helped some parents to understand the uniqueness of their child and determine what it meant to be a parent of a child with autism. For example, parent #12 shared:

The positive reinterpretation, which has emerged after a long caring experience, above all assisted me to understand what it meant to be a parent of a child with autism. ...It has helped me to manage and make sense of the challenges that came along with autism.

Well, my son is very unique; he is slightly different from my other two children... I could say very differently living in his world. Indeed, life is not easy for parents like me. But having a positive outlook has helped me to think of the paths for the challenges in life. ... If you manage the challenges, it reduces the stress and burdens. At least you would get to know what to do (Parent #7).

Some of the parents' coping processes included reconceptualizing what is 'normal' for themselves and their families. As a coping process, reframing the situation and thinking of their child as a blessing has helped them to adjust to routines, and maintain continuity and predictability in their family, which can be described as a readjustment to the 'new normal.'

Parent #10, a father illustrated:

It's not easy to redefine and start thinking of everything as 'normal'. The way we look at life at the moment is very different. We as a family, [including my wife and other two children] have redefined things as 'normal'. He is our child and an individual with a special need. What we did was, taking our child as a blessing; everyone is willing and working to help him. In this way, we have adjusted routines, maintained continuity and predictability in our family. I think we have got an interesting perspective in life that would make a huge difference.

Some parents view their children as unique and extraordinary in their own right. Acknowledging the uniqueness of their children, though not explicitly stated, has reframed thinking towards developing a supportive relationship with their child and focusing on helping their children. Parent #4 stated:

My child just sees the world in a different way than other people do. He has got different software... The key for parents is to make that connection, to see the world from the child's point of view, and work within that framework. I hoped other people would understand this.

I don't give much attention to what other people say; honestly, you need to develop a thick skin for that...Just she notices and looks at the world differently. What I have to focus on is helping my child to be equally able and deserving. We have to support her to improve her skills and abilities. I encourage and I would say come on, you can do it, to reinforce and capitalize on the strengths. As a parent, I have seen and feel this works a lot (Parent #9).

4.4.1.4. Coping through Advocacy (Educating oneself and others about Autism)

Educating themselves and others (advocating) about autism is another positive strategy used by parents to cope with raising children with ASD. The participants reported the importance of knowing and gathering available information regarding their child's condition and its associated challenges on the children and parents. Parents should seek out information and support during and after the diagnostic process. Some have turned to the internet, others to the child's teachers, or to trusted friends. Still, some parents reported other people such as other parents of a child with autism as a great source of information and knowledge to educate themselves on many aspects of autism because they have similar experiences or concerns. For instance, parent #11 indicated:

Sharing information with other parents of a child with autism has helped me a lot to learn and have knowledge about the disorder and even to be acquainted with easy ways of training my child. For example, reinforcing little improvements rather than following a punitive approach, which I have learned from my friend, is helpful. I am also teaching different life skills and her psychomotor development is improving from time to time. ...moreover, talking to other parents and learning different strategies has really reduced my emotional stress and also assisted me to see a change in my child.

In describing other parents as a source of information, the key informants from both centers also affirmed the experience-sharing session in a ‘parents support group’ established by both centers as very helpful. In the groups they talk about the progress of their kids, the challenges they are facing, and how they are coping with the challenges. The parents share information and learn from one another’s experiences (the details will be presented under the theme, available supports).

Some of the participants shared that the information they are acquiring from the internet and different websites helps them to get updated and build upon their knowledge. In this regard, parent #12 reported,

Reading information from the internet, websites, and recently published articles have created a huge difference in my life. Now, I think I have a detailed understanding of autism, do’s and don’ts in educating the child, in toilet training, dressing, eating, and other life skills. This is not easy; it makes your life simple and nice.

Similarly, parent #10 said,

After browsing the internet and building up my knowledge about autism, I have stopped blaming myself, I am receiving and using up-to-date information and my child’s situation is also improving...

Other participants shared they are trying their best to teach and raise awareness about autism especially when they face stigma (like blaming look) and/or when they get the chance to speak with people. Parent #7 conferred,

What I noticed as a major problem in this country is the public is not aware of autism. Anywhere I go, especially in a public place or hospital, without knowing the problem, people over stare or give you a blaming look or tell you what to do to properly socialize your child. When I see and read these kinds of things even in their face, I will tell them he is autistic, or I would ask them the question, have you heard about autism? The answer is most of the time, no! Then I will start explaining about autism. ... You know, if the community is aware of the situation, life would be easy for the children (they would be well integrated) and parents too (stigma and discrimination would be reduced).

4.4.1.5. Coping through Patience and Perseverance

Most of the parents claimed patience is an important coping response in caring for a child diagnosed with autism. Parent #6 explained the significance of extreme patience and understanding in socializing her child:

You just have to be so patient. Even though I'm going crazy or I get mad sometimes, I couldn't treat her as my other kids, rather I assist her to understand and instruct how things are done or the way to do things.

... I'm quite patient and still work on it, hence; every morning, you have to wash her face and hands, feed, prepare and take her to the school, picking from the school, you have to explain and repeat more on very simple matters, whether you are tired or not. She might be sleepless sometimes, and expectations can't be there. ... I think patience and perseverance are critical to cope with the challenges of raising a child with autism (Parent #11).

Patience helped many parents to regroup their thinking, give time for their child to process information, and prevented the situation from escalating. Parent #8 explained how she tried not to inflame difficult interactions with her son:

... I think a lot of patience. ...when I sit back and wait a bit rather than just diving in (if not dangerous), and come with an alternative, things will be fine. If I don't give him time to think [and process information], he is provoked to be quirky and annoying. I think patience would give him room to reorganize his thinking, preventing us from escalating issues and helps me to have a good and positive relationship with my child.

Another strategy is perseverance. Perseverance was a critical component observed in most narratives. This persistence is a key component to resilience building. When participants spoke about their sense of parenting responsibility, they expressed the view that the need to persist rested solely on them.

Parenting is challenging by itself. Parenting an autistic child is highly challenging more than you think because it demands much more of you. In the process, it makes me patient, repetitive, and unreservedly, dedicated. ...I have no option other than being persistent to carry out my parental responsibility (Parent #4).

Similarly, parent #12 explained:

I think I felt obligated to meet the needs of my autistic child, my wife, and the typically developing children. To adapt more and make the situation 'new normal,' I should have to be responsible for the family's wellbeing [to stay together and address the challenges associated with autism], persist, and be committed.

4.4.1.6. Coping through Seeking Social Support

Seeking social support from spouses, friends, relatives, and other parents: As they encountered challenges, most of the participants repeatedly showed renewed determination to seek help. Seeking help was a vital coping strategy for the participants as they attempted to manage the difficulties of raising a child with ASD. The parents indicated they sought help from

different sources such as the internet, hospital, religious places, trusted friends, their child's teachers, and other parents who had a similar experience.

When I see and decided there was something wrong, I started putting holy water on the forehead of my child, moved to health centers and hospitals repeatedly. I have also consulted my close relatives, and everyone I was able to discuss with. Without telling my ailment, how do I look for the solution? (Parent #11).

The participants spoke of different kinds of social supports that helped them reduce the psychological and social challenges associated with their children on the spectrum. Many parents in the study cited the support they received from extended family, close friends, and other parents of children with ASD as particularly valuable. Accordingly, parent #6 discussed,

...I don't think I would survive without the help of my close friends, and relatives. They will tell you about different life experiences to help you understand my child is better, compared to children with different special needs. When I discuss with people, I would get relief. Some would advise me to be calm and keep working hard. ...especially my mother would sometimes come and help with my domestic chores. This is not easy to reduce the psychological and social burdens. At the back of my mind, I always think, I have at least someone to understand my situation and help me if I need it.

The beneficial effects of connecting with others, within and outside of the family were apparent in parents' narratives and helped them to cope better with the challenges. A parent benefited from sharing their troubles with a trusted family member (be it their partner, mother, sister, and/or fathers), which participants reported as helping them to cope better in dealing with the challenges of ASD.

Seeking Support from Professionals and Organizations: Parents also sought support from professionals and organizations to alleviate daily pressures; recover from and prevent subsequent crises and address the weaker areas of their child's development. Overall, parents

noted the lack of appropriate and timely supports from (especially, government), health centers, and hospitals. Though not satisfying, participants also spoke of useful support they sought after diagnoses as:

It was very tough before the diagnosis; it took almost three years to know it was autism. After diagnosis, though I have paid a lot and am not satisfied, medical professionals have given him different medications and therapies. ...I have seen more rapid progress after my child was admitted to the center. The center has reduced a lot of burdens for me. Because of the center, I have continued my job (until my retirement by pension), attend social events, and above all, my child is learning different skills including how to interact with people (Parent #5).

The parents also reported that they have consulted the doctors when they faced problems; observed progress or when they wanted to take action. In addition, searching for alternative treatments for the children was another strategy and parents tried different kinds of treatments in searching for a cure and healing of their children. Holy water, prayer in churches and mosques, and traditional medicine are other strategies used by parents.

According to the key informants from Joy and Nehemiah Autism Centers, the point of interaction between the center and parents would start when parents received information through professionals, mass media or other parents of a child with autism and come to seek help from the center. The education and training of the children (i.e., to improve eating, communicating, toileting, walking, and other social skills along with professional counseling, transportation to and from the centers, technical support and awareness-raising training provided to the parents) is helping to make a visible difference in managing and coping with the challenges. All the participants also revealed they can freely discuss any issue related to their children's behavior (without any fee) with psychologists and teachers in the organizations and together come up with solutions.

However, from the in-depth and key informant interviews, one can infer that all children diagnosed with autism will not be immediately accepted to the centers due to capacity limitations and the focus of target groups. As a result, around 900 children with autism are on a waiting list at both centers. In admitting the children, Nehemiah Autism Center gives priority to female children between the ages of 3-8 years. Their main reason is female children face a more complex problem with sanitation, especially at puberty. The other reason is (the above specified years of the children is delineated) to train and graduate/prepare numerous children within a short time for the formal school curriculum. Based on their experience, most of the time children within this age range can improve quickly, learn and adapt more than children over the age 9 years and above. On the other hand, Joy Autism Center appears to accept children that are more severely affected by autism. The rationale for such a focus is that children with less severe problems are better able to cope in the 'normal' environment and therefore it is believed priority should be given to those with more severe problems. Consequently, services are initiated upon diagnosis and assessment of the children by Joy Autism Center professionals and enrollment is based on available spaces.

Regarding the help-seeking behavior in general, some key informants reported that they believe and suspect that a higher number of people with an autistic family member are not seeking medical care, as they considered this to be a result of sin, and thus opt to look for spiritual solutions through prayers or holy water.

In conclusion, parents with good social support, from their spouse, friends, relatives/extended family, and/or an organization seems appreciative for the smallest improvements made by their children, accepted and normalized their children's autism disorder, and expressed hope on the prospect of their child's the future. Finally, it was revealed that parents were responding and coping with the challenges of raising children with ASD through

religion, acceptance, reframing, advocacy, seeking information, and various forms of support as positive coping mechanisms.

4.4.2. Coping through Negative (Maladaptive) Strategies

Very few participants talked about how they avoid others (use avoidance as a strategy) in order not to talk about their child. They also mentioned that they don't feel comfortable discussing their child with everybody because of the fear and discomfort of letting people know and seeing the reactions. For instance, parent #1 illustrated,

I don't want to discuss my child with everyone unless I think it is useful for me. I can openly discuss and share concerns with the professionals in and outside the center, other parents of a child with autism, and very important relatives. If I would tell anyone, what did I get? I might see them sucking their lips or discomfort that would just make me feel bad.

Parent #2, is a widow and working single parent who preferred to use avoidance coping strategy when she feels stigma and discrimination.

I would try to make it secret because people think as if it is a punishment for my prior sin. I will avoid people if I feel stigma and discrimination. For example, I am not comfortable discussing with one of my neighbors. They would not allow my kid to play with their children. Thinking she would harm their kids. ...So I am not comfortable telling or disclosing to anyone as a way to be safe from the stigma and discrimination.

In sum, in moving through their journey and managing all the challenges, the participants were in constant interaction with their environment. To manage the challenges, as identified from the participants' narratives, the coping strategies employed by different parents are diverse. The different coping mechanisms used by parents to tackle and overcome the challenges were categorized and presented as positive (coping through religion, reframing, acceptance, advocacy,

patience and perseverance, and seeking social support) and negative strategies (through avoidance).

4.5. Available Supports for Parents of a Child with Autism

Having sufficient support is crucial in parenting a child with autism. Several participants expressed the view that effective social support is significant for a parent of a child with autism. Various support systems mentioned by the parents and key informants were organized under the subtheme, informal and formal supports. The participants identified informal social support systems that included spouses, siblings, relatives, friends, and other parents of a child with autism, religious leaders, and other members of the community. On the other hand, autism centers and professional services were categorized under a formal support system. Participants claimed the supports were a source of their strength and helped them to make parenting somehow a manageable process, and allow them to hope for a bright future for their children and themselves.

4.5.1. Informal Support

Human beings have the innate ability to form a relationship and bond with others. These relationships have primitively protected the human species from harm and destruction by cooperating and fighting enemies for their collective survival. In a modern world, through relationships, people depend on one other to celebrate their joy and manage their stresses and challenges. Similarly, some parents of a child with autism draw on their informal social network that included spouses, siblings, relatives, friends, and other parents of a child with autism, religious leaders, and other members of the community. Informal support coming from family members, friends, and in some cases, neighbors vary from one parent to the other.

4.5.1.1. Support from Spouse

All male participants claimed they have received positive support and reacted positively towards their wives' conditions. Their wives were helpful, caring, hardworking, and willing to talk about plans for their children's care. For example, parent #10, husband of a housewife and a father of three children said:

...You know, even if it is now changing, in our culture, women are entirely responsible for domestic chores. Though I could seldom help her, she could do almost all housework by herself including caring for the [autistic] son. For this reason, I could say, she is so caring, hardworking, a good mother, and a good wife. My wife was my pillar during this entire long journey. There are so many things I could've not done without her. Let me give you an example of how caring for autistic children is difficult, our child [with autism] doesn't know how to remove the hair from his private areas. Until very recently, someone has to help him with a toilet, clothing, and feeding him. To that extent, mostly, it is his mother that deals with that. In addition, she is also caring for me, the rest two [typically developing] children, and management of domestic chores, though we may have the housemaid or not.

Similarly, some mothers receive positive support from their husbands. The lack or absence of the spouse's support is an important contributor to parents' levels of stress (Meadan et al., 2010). As parent #8 unequivocally states hereunder, positive spousal and/or familial support can make a powerful difference to a mother's quality of life and her ability to support and nurture her child.

The most important support anyone can find is within the family. I am grateful to have a supportive family, especially my husband, who understands and helped me through all this. It makes a difference in my life and ability to care for my all children [including the autistic one]. He supported my decisions when it comes to the children, and he helps me a lot in choosing what is best for them.

Parent #1, who is also receiving support from her husband, feels comfortable and relaxed when talking about her husband and how he fulfills his responsibilities towards their son particularly when it comes to things that the father usually does. In sharing her experience:

My husband was very supportive and cooperative; he is helping me a lot. Unlike most fathers, my husband does take responsibility for our son's care to extent of going to the toilet with him.

Parenting a child with autism is not easy for the parents and spouses; supporting one another is generally essential. Three mothers complained that they received little or no support from their husbands. These mothers testified they received little support, patience or understanding from their families, especially their husbands. Parent #3 described her spouse in response to their child:

My husband did not support me not only in domestic chores but also in not attending the follow-ups in the hospital and autism center's care and treatment. He is so ignorant. If anything happened while my child is in the center, they'd call me and not his father. Sometimes, I had to go and meet the teachers in person, and they are so cooperative and very good people.

To accept, understand, and live with her husbands' indifference, disinterest or simply lack of support, parent #3 further excused her husband's behavior because he blamed her for their child's autism. As she further elaborates:

My husband is not supportive and understanding from the very beginning. When this situation happened, he refused to accept for two years insisting the child is affected by an evil spirit. He continually blames me as if I am the cause and if I ask him to join me in his medical follow-ups; he wouldn't be happy and sometimes shout at me saying it is your responsibility...

Some mothers still experience blame, lack of care, and support. Parent #7 suffered from her husband's angry refusal to accept the inevitable fact, autism, and their relationship became distant, ending in divorce:

... in addition to the complex and difficult nature of autism, my husband's angry denial and contending me with the blame of causing autism. I was busy with my job during my pregnancy period. He thinks autism is caused by poor care in my prenatal period. That has later led to divorce in our relationship. He hasn't accepted Eyob. Instead of helping me, he always blamed me and accused me of spoiling the child, which makes me to grief and cry every time he said so. He is not good and does not care about us. It became so hard and we ended up in a divorce.

Some fathers withdrew from their child's lives as a coping mechanism in response to a condition they did not understand. They did not want to get involved in child care, as parent #6 describes:

I am fully responsible for my child. When she had tantrums, her father didn't know how to handle her. Like other husbands in our community, he did not want to get involved in children's care. I stopped my full-time job and going out, stayed away from everyone including relatives and friends. I decided to dedicate myself completely to my children. ...but without a supportive husband, things become sometimes unbearable.

4.5.1.2. Support from Siblings

People use different strategies and resources to keep themselves intact. Nearly half of the participants' used other children or siblings of the child with autism as the resources. Even if the extent and the kind of help varies, and not all the children are supportive, parents reported that their children are the source of their support in terms of caregiving, socializing, and helping with domestic chores, to reduce the parents' time demands, psychological and social challenges. Except for three participants, parents who have other typically developing children, reported that

they are supported in the caregiving. For parent #8, a mother of three, the extent of their caregiving was much appreciated:

My children are really helpful. They both help their brother in any way they can. When I'm not around, his sister or brother was the one who takes care of him [autistic child]. There are times when my husband and I might not be home because of work but since we have strong support from our other children at home, we are continuing to do our full-time jobs.

Many parents reported having positive experiences with their other children. Parent #7, another mother, described how her daughter has helped her autistic brother:

She loves her brother and helps him as much as she can. Especially, she taught different skills on how to do things. I always give him instructions but he would often not listen. His sister follows a completely different approach. She would do first, for example, how to wear clothes and ask him to imitate her. Then, he can easily imitate and do things. She is so helpful and caring.

However, not all parents received this kind of support. Parent #3 had little support from her other child:

...just like my husband, my younger son does not care. He makes him scream and cry by taking his toys and property. Even if he is younger than his brother, I would continually advise him saying: he is your brother, he is autistic and you don't have to do this and leave his toys for him—you have to support your brother. He listens, but repeats the same mistake, as he is also a child. Occasionally, I would hit him out of frustration.

Parent #4 described how Eyuel's older brother would be very ashamed and embarrassed by his brother's behavior when going out in public places and did not want to get involved:

Eyuel's older brother is not supportive. Mostly, he would be embarrassed by his brother's behavior. He sometimes screams in public places, throws food, or has tantrums. This makes him feel ashamed and embarrassed when other people are staring in public places. He doesn't want to go out in the presence of his brother.

Some parents reported they are in a demanding situation due to the complex needs of the siblings and a child with autism because much attention is given to the child with autism often at the expense of other children. For example, parent #11 stated:

...Of course, my autistic child is always at the center of my attention rather than other children (her brother and sister). They would often complain as if I am favoring her [the autistic child] and that makes them feel jealous. I would tell them not to compare themselves with her [the autistic child], as they at least could complain and properly ask for their rights, which she doesn't.

4.5.1.3. Support from Relatives, Friends, and Neighbors

Other parents claimed to have support from extended family members or relatives, friends, and neighbors. These supports vary from acceptance to financial, in-kind or physical assistance in domestic chores. Parent #2 was supported financially by her relatives and mentioned her aunt and older brother as a source of support:

[Taking a long out-breath], I can't tell what I am in or passing through... From the very beginning, I am illiterate, a widow, and a destitute woman. So I don't have anything except the income from petty trade and daily labor like washing clothes or baking Enjera if I get it sometimes by chance when our neighbors or other people whom I have known have some social events such as birthday or wedding ceremony. Yet, I have an aunt and one older brother; they help me with intermittent little money for the medications and during holidays. However, they are reducing their help from time to time. Uum... because I think they are fading up and they do have their own family [wives and children] to care for.

Similarly, most family members of parent #1 were supportive and helpful towards a mother of two children. Acknowledging the contribution of her mother and younger sister, she explained:

Everyone around me did everything they could to assist. My husband and another child would try their best to help me. My mother and younger sister are the ones who was always there for me. I was always calling and talking to them when I face a challenging situation, emotionally, financially or anything. ...I consider myself very lucky for having so much support around me; it was a blessing to have them in my life.

Parent #12, a father of two children, remarked that he also finds good emotional support from friends and extended family members:

I have very good friends and relatives, who are capable of encouraging me to keep going. If my friends have accepted my situation and understand me it is enough. My relatives would also help my wife in domestic chores and in caring for our children whenever we are going together with my wife to attend social events and ceremonies.

Parent #8 had supportive and helpful neighbors, who helped her overcome her distress and to see positives in her child:

I will never forget my neighbor's help. She is the reason after God, to guide me on what to do with Yafet and how to help him. ...She tells me that Yafet is intelligent and different from other kids in a good way. Whenever I feel depressed because of Yafet's condition, she reminds me that he is a good boy and that his differences are positive.

4.5.1.4. Support from the Community

Societal support includes awareness, others' reactions to autism, and the availability of social networks. In a study by Smith, Greenberg, and Seltzer (2012), having a supportive social network increased well-being. Educating the public about autism also improves others' attitudes towards the disorder (Martin & Bassman, 2012) and might inspire a societal change. The other question raised to the respondent is, do you think you are living in a community supportive of the parents and children with ASD? Responses indicated that the societal response to the participants and their children with autism has both positive and negative connotations.

Accordingly, very few (only three) participants of the study reported they experienced positive responses from the community towards themselves and their children with autism. These participants feel they are living in a supportive community that consistently shows sympathy and love to them and their children with an autism spectrum disorder. They believe the care and treatment from the community had a positive meaning. As participant #12 explained his experience:

... Now knowledge and awareness of autism are increasing, I didn't face a serious challenge from the community. So far, I didn't see anyone negatively treating my daughter and affecting my feelings and emotions. Even when they know that she is autistic, people would be cooperative. They even allow playing with their children without disability in harmony and unity. ...in the future, I hope the community would be more integrative and my daughter would also have a job and better career development.

Similarly, parent #10, a father, also had a positive viewpoint and received sympathy and love from the community that encourages and creates hope:

People are becoming more knowledgeable about autism now. When I tell them my son is autistic, they would immediately show sympathy and love towards my child and me. Their attitude is more or less changing and becoming good. I think it would be also better than this in the future.

The participants in this study bear the burden of providing care for their sons and daughters with autism, and as the data revealed, many of them struggle with a judgmental society that lacks awareness of their feelings as parents of children with autism. Behaviors such as over staring and laughing hurt not only the parents but also their sons and daughters as well. Parents' responses to these negative reactions varied. Some, for example, decided to take action by raising awareness of autism and being active in events (meetings) and support groups. This is how parent #4 mostly reacted:

Personally, whenever I talk to people, I work hard to spread awareness about autism, I frankly talk to them about autism, the challenges I am in, explain to them what to expect from the community and the wider system in general.

Unsurprisingly, five of the parents stated that social attitudes towards them as a parent raising a child with disabilities was challenging (thinking the community is not understanding of their situation) and they mostly decided to ignore judgmental gestures and comments, and not pay attention to what people said. As parent #3 shared:

I think the awareness among society is far behind and as a result, the community is still somehow judgmental and not understanding... if I say, for example, I am too busy, I need money or I didn't sleep last night to someone who doesn't have a child with autism, that person might not understand and would never comprehend the feelings and the emotions I am struggling with. ...I might often see people's bad gestures or comments. So, in this case, I will ignore and keep taking care of my son.

The parents' social networks have a significant role to play in obtaining support. For example, talking to someone is a widely used strategy by most parents. Some parents have a preference with whom they want to talk. The parents who preferred to talk with people having the same problem reported they understand one other and share their experiences. As parent #2 shared, *"I have a friend whose child is also sick and I usually preferred to talk with her because she can easily understand and feel my pain."* Spouses, other children (siblings of the child with autism), relatives, friends, neighbors, and people with similar problems are the informal supports whom the parents have relied upon. The data revealed that at least one of these sources of support was mentioned by all the participants of the study.

Generally, having a child with ASD is demanding for a parent and requires looking for support from their informal social networks. In the above extracts, it is clear that whatever

support parents receive, whether it is in kind or cash has inevitably an affective dimension. Good support seems to result in gratitude, prevents loneliness, and creates a sense of belongingness and worth. Conversely, lack of support for many, if not all parents, would make them think and worry about the future and the well-being of their children.

4.5.2. Formal Support

Having explored informal support for the parents, the formal supports parents are receiving were also explored. For all participants, Joy and Nehemiah's Autism Centers were providing support and they were very grateful for the founders, the management members, and staff in the organizations. The participants' experience with using formal supports is discussed in the following section.

4.5.2.1. Overview of Supports and Services in Joy and Nehemiah Autism Centers

Joy and Nehemiah's Autism Centers are two different institutions that provide similar services to children with autism and their parents. Medical evidence and certification of children with autism are vital and are the first criteria for membership in the center. The services offered for the parents or caregivers by the centers could be broadly categorized into professional advice (counseling), psycho-education, and awareness-raising training. Except for a slight difference between the two centers in the mode of service delivery, degree of parental and key stakeholders' engagement, the service packages and supports are similar. Roman, a key informant from Nehemiah Autism Center described the services and supports provided by the center in the following way:

... Far beyond the self-help skills for the children with autism, the supports and services by our center for the parents and community would be grouped into three. The first is

giving our professional advice to parents and caregivers when they seek professional opinions on autism. The second is providing training and psycho-education for parents of children with autism accepted by the center. The training helps the parents with how to deal with and manage the behavior of autistic children. The third is an awareness-raising program for parents of autistic children on a waiting list and the general public through mass media (using electronic and print media), seminars and workshops.

Similarly, a key informant from Joy Autism Center indicated that the organization is prudently working to improve the situation of children affected by autism and their parents. The organization intervenes at three levels with different approaches: Individual-level, parental (familial) level, and school and community levels. The individual-level intervention is the main objective of the center, which focuses on helping children with autism to develop self-help skills, dealing with their behavioral challenges, and providing them an enabling and supportive environment. In connection with this, the children learn how to use the toilet, cook, explain their needs, interact with others, write, paint, and computer skills. In addition, they are also practically supported by participating in different social events and shopping activities.

The parental (familial) level intervention is aimed at enhancing the capacity of the parents of the children with autism in understanding and responding to the care and support needs of the children. The center's programs offer the parents skills, knowledge and support in coping with the situation. Thus, the services benefit both the children affected by autism and their family members in creating a better living environment. This is also true with Nehemiah Autism Center's services.

Furthermore, Joy Autism Center is working with wider members of the communities and primary schools in Addis Ababa and its surrounding special districts (woredas) to raise awareness of the issue and increase responsiveness of the concerned bodies. Currently, the center is supporting and working with thirteen primary schools (eight in Addis Ababa and five in Addis

Ababa surroundings special woredas). The purpose of the partnership is to train teachers on autism and make sure that children with autism (that are integrated into primary schools) are supported in the school environment. On the other hand, community-level interventions aim to raise awareness of autism among the public in Addis Ababa city and the surrounding special woredas.

Generally, as most of the reports of the participants and key informants of the center revealed, Joy and Nehemiah's Autism Centers were established in a healthy and friendly environment for the children and are equipped with basic and necessary materials to provide services. However, the adequacy and qualification of the staff are a serious cause of concern for the key informants. According to Abel, a key informant from Nehemiah, *"Whether you believe it or not, from fifty universities of Ethiopia, none will specifically train professionals for providing care and support of children with autism. What we did was we have hired professionals trained and graduated in special needs and provide them with short-term training and on job seminars by professionals from in and outside Ethiopia. Sadly, we don't have trained human resources on the market in this profession."*

There are 20 teachers in Nehemiah and 18 in Joy Autism Centers. The teachers' educational backgrounds and expertise in the area are significantly different ranging from grade 10 to first degree in special needs education, educational psychology, and a B.Sc.in Clinical Nursing. The centers attempt to improve the knowledge and skills of their staff via training designed to further develop their knowledge and skills. There is also mentoring and coaching of the teachers in the centers by the program management and education specialist (in both Joy and Nehemiah Autism Centers). Apart from this, the majority of the participants reported, after joining the centers, the children's interactions, behavioral and communication skills have improved and are improving from time to time.

4.5.2.1.1. Types of Services provided by the Centers for the Parents

Psychosocial Support: As identified by participants, training (for children and the parents), counseling, monthly parent discussion seminar, and the opportunity to earn a living for destitute women-headed households at no cost were the psychosocial supports provided by the centers. These supports were not available (inaccessible) for parents whose children are not admitted to the center.

Training

On-job training for teachers and caregivers in the centers: Teachers and caregivers in the centers receive on-the-job training for continuous professional development. As mentioned by the key informants from both centers, on-the-job training is provided for the staff in the organization mostly by the guests from both in and outside the country. The teachers and caregivers do not have certificates or diplomas in the area but they are getting the opportunity to take on-the-job training on autism and how to provide care and support for children with autism. One key informant from Nehemiah claimed, *“There is no any university or college that provides a degree or diploma or even a certificate on autism care and treatment. So, we are hiring any special needs education or any graduates of psychology and we offer short-term training on how to provide care and support for children living with autism.”*

Counseling and Training for parents: Counseling and training are provided in both Joy and Nehemiah Autism Centers. For parents, these played an essential role in helping them to become aware of the situation. Counseling sessions could be arranged for the parents based on their needs by the psychologists on issues they want to discuss with the professionals.

Capacity-building training is given once a month for parents on different topics related to autism. The participants of the study pointed out how their lives were changed after their children joined the centers. The centers are depicted as playing a vital role in developing their competency by guiding them and showing the way to help their children. The trainings are beneficial in upgrading the parents' awareness of autism. They met once a month to discuss and exchange ideas about the changes, improvements, and challenges they have faced in dealing with autism. They discuss, share, and learn from one another's experiences as parent #10 articulated:

In our monthly meeting seminar, we can raise and discuss everything that concerns us, such as possible causes of autism, communities' perceptions, and reactions, do's and don'ts in caring for our children, how to manage their behavior, challenges we are facing, mistakes made earlier, best practices on positive ways of coping, some tricks to enhance the social and communication skills, improvements we have observed and many more. I have shared my experiences too and above all, gained and learned a lot from the monthly meeting seminar.

During these monthly meetings (for experience sharing) the parents are provided with the necessary information about the status of their child and they discuss how to support their child with the staff and owner of the organization. The vast majority of the parents mentioned they take this monthly meeting as an opportunity to discuss and share experiences with other parents of children with autism, as parent #7 demonstrated, *"I think the monthly meeting provides us with the opportunity to communicate and share experiences with someone who is in a similar situation."*

Based on the information from participants and staff key informants, the training provided by the organizations is not only given to the parents. Caregivers or anyone who has the

responsibility for the child with autism are also eligible for counseling, training, and monthly meetings.

Transportation, Lunch, and Opportunity to Earn a Living: Transportation in cities like Addis Ababa is very challenging due to the lack of a good transportation system; however, both Joy and Nehemiah's Autism Centers were able to provide transportation service for the children. The respondents indicated that their children are using the center's free transportation services and provision of lunch. The centers provide door-to-door transportation services for the children and lunch provision free of cost for all children. For example, parent #6 revealed, *"It is a great opportunity to have transportation services from the center as it saves our time, energy, and cost."* Thus, both centers have tackled the transportation challenges in this way.

In addition to providing free transportation and lunch services, the centers provide the opportunity to earn a living for destitute women-headed households (impoverished mothers of a child with ASD). According to the information provided by the staff key informants in both centers, they are working to support women with severe financial constraints. The organization provides a certain amount of initial capital (seed money) for women who are living in extreme poverty and allows them to start a small business as per the preference of the parents. Once these parents are involved in producing products, the centers also strive to find and link them with a market to help them sell their products.

4.5.2.1.2. Improvements and Benefits of the Centers for the Parents and their Children with Autism

The centers make a great contribution to children's and parents' well-being. Participants identified that the centers enabled the children to visibly change in various aspects, creating an opportunity to meet and play with children with the similar condition, have access to play items that are not affordable at the individual level, and gain learning skills through school attendance. Such contributions by the centers have played a vital role in improving the behavior and social skills of the children. The key informant (a teacher) from Joy Autism Center stated:

Children with autism are provided training on the development of self-help skills like brushing teeth, taking a bath, putting on/off clothes, washing underwear and socks, sorting and placing clothes in kind, cleaning and placing objects properly, cooking fast foods, socializing with other people, attending events and observing ground rules (like traffic rules, conforming with rules at market places and recreational facilities) are all clarified and this has enhanced trainers capacities. Almost all of the trainees are performing well after the training and the parents are also observing tangible changes.

Furthermore, all the participants have pointed out their life was changed after their children were admitted to the centers. For the majority of the participants, these schools have provided them with relief from the stressful and challenging day-to-day activities of caring for their children. Parent #9 illustrated, *"I felt relief after my child has joined the center."* Similarly, parent #5 has explained the contributions of the center as:

The center [Joy Autism Center] is completely remarkable. The founder of the center is also awesome. She does every effort unreservedly to help us. It's really interesting to take support from this kind of center. I don't have a lot of emotional support even; let alone buying the material and affording the training of my child. I don't know how to thank her for the contributions and changes she [founder of the center] is making in our lives.

The main supports for the parents were: child socialization, counseling and training for parents, parent socialization (training and organizing monthly parent discussion/meeting club), and transportation and lunch services free of cost. Parent #4, a father, who participated in the in-depth interview, noted how the school has improved the situation of his child:

Before joining the school, my child was very isolated and not easily communicates with other children. After he joined the center and mixed in with autistic children similar to his situation, I have observed a lot of changes and progress in how he integrates, communicates, and plays with the children. This is great and a change that has to be appreciated.

Almost all parents in this study recommended that similar centers should be established in different parts of the city and throughout the country so that other parents in a similar situation can benefit from the service packages. They reported both parents and their children benefited a lot from the centers. Most parents described it as an exciting experience to see their children's socialization, improvements, and even playing with other children in a similar situation.

4.5.2.1.3. Strengths and Challenges of the Center-based Services

4.5.2.1.3.1. Strengths of the Center-based Services

In terms of the strengths of the services, the participants involved from both centers identified and appreciated the physical environment of the centers and good communication between the parents and teachers.

Physical Environment of the Centers: The participants described the centers as favorable and conducive for children with autism. Besides the participants' response, in so far as the observations of the researchers were concerned, Joy and Nehemiah's Autism Centers were physically well-fenced. The respondents (both in-depth and key informants) said each center is

conducive for children in terms of the classrooms, toilet, sink for hand washing, and shower room for children with autism. The centers' employees have good personal relationships with each other and are cooperative. The centers were equipped with basic and necessary materials for the training as well as teaching purposes ranging from toys to musical instruments. In addition, the children sing, dance, and engage in physical exercises freely in the school's compound. Hence, they pass the day through refreshing exercises. Even if both school compounds are narrow, they use them properly and effectively for bicycle riding, basketball-playing, and a variety of outdoor games. Moreover, the administration office and the corridors are decorated with pictures and photographs. Generally, all participants in the study acknowledged the different types of support provided in the centers. It is a lively atmosphere for the children with autism, and the parents feel safe, happy and are encouraged to bring them to the center. For instance, parent #7 described:

My child spends the day here in the center and benefited a lot. I am so happy. As you can see, the physical environment is well-fenced and I feel safe. ...There are different kinds of toys and equipment. The manager and teachers are also helpful. The training given for the children is good and bringing a tangible change in their psychomotor development and skills.

Communication between Parents and Teachers: All the participants reported the communication in both centers' personnel and the parents as active and positive. Communication with teachers was effective as parent #9, a participant from Nehemiah Autism Center stated, "... *We have two-way communication. I could come and take counseling whenever I need. I am attending each monthly meeting. The teachers in the center will also call me if my child is sick in the center and I could come to take her to a clinic. I think I have good*

communication with the owner, teachers, and caregivers in the center.” The key informant from Joy Autism Center also claimed,

We are using communication book, phone, and face-to-face contact as a method of communication with the parents. Whenever we feel we have to call for the parents, we will discuss together and call to let them know what happens (for example, if the child is sick). We are also involving parents to convey information to the teachers (usually in monthly meetings) of our center to develop the quality of services or care and treatment of their children.

The data gathered from participants revealed that both centers keep a record of the children with autism and notify the parents on the child’s progress. The record formats include the child’s challenges, their perceived solutions, and the type of instructions given to them which aimed to improve their self-help skills in the school as well as at home. They commonly use the communication book to keep track of the child’s difficulties and progress. Parents exchange information with the teachers and center personnel through the communication book. They describe home-related daily living challenges in the communication book to inform the center for the provision of better interventions. To triangulate the information collected by interview and key informant, the researchers easily accessed the communication books. There is an exchange of information that differs from one parent to the other and parents’ active engagement is also confirmed by their comments and signature in the communication books.

4.5.2.1.3.2. Challenges of the Center-based Services

The participants spoke about the challenges or unmet needs of (Joy and Nehemiah's autism) center-based service as lack of resources, lack of support from the government, difficulties of accessing specialized materials, and lack of organized partnership between the stakeholders.

Lack of resources: The participants reflected on the lack of resources in terms of funding and trained personnel. The key informants from both centers revealed there is a scarcity of budget to cover the administrative and running costs. The financial sources of both centers are based on donations from domestic and foreign-based organizations. The funding fluctuates based on the donations and neither center is financially stable.

Lack of trained human resources: The centers should be organized with knowledgeable and skilled professionals concerning autism, including the causes and characteristics of autism, assessment methods, interventions to meet the unique needs of each student, curriculum, environmental adaptations and accommodations, instructional methods, strategies to improve communication and social skills, and classroom and individual behavior management techniques. However, the key informants with the centers' management and staff noted that the centers are challenged by the unavailability of trained human resources in the labor markets of the country.

Almost all the key informants reported that there is no tertiary educational institute in Ethiopia that effectively prepares psychologists, teachers, and administrative staff to be knowledgeable or skilled in the area of autism. As a result, the centers rely on special short-term training given to the teachers at the center rather than recruiting ready-made professionals. A key informant from Joy Center (member of management) stated:

Without this expertise, the schools could not effectively manage children's challenges, and instead, it would only be 'a babysitting center.' For instance, when we hire the staff, most of the teachers had a narrow understanding of autism, do not know the significant heterogeneities within the spectrum, unaware of evidence-based interventions, such as Applied Behavioral Analysis (ABA), or PACT (Preschool Autism Communication Therapy) and therefore, they were unable to reinforce the behavioral techniques used with the children. ...the other challenge is a high turnover of professionals. You know, when the teachers took training and have the experience, because of the low salary, they would leave the center and make money by themselves, whether they have been licensed or not. The people on a waiting list with no other options or who can pay the money asked by the professionals (500-700 birr for every hour spent with children) would employ them...

The parents also described the inadequacy of specialized professionals, such as licensed occupational or speech therapists, even in exchange for fees when necessary, and noted that this prevented the parents from accessing the services outside the center and addressing their children's needs. Parent #8 noted that:

There is a paucity of ASD-specific expertise in our community. In looking for the professionals through my informal social networks, I came across one person with a B.A. degree in Psychology, not licensed, who took short-term training and has work experience in Joy Autism Center. To your surprise, he asked me for 700 Ethiopian birr for every hour he would spend with my child. That is too costly, which I can't afford to provide additional assistance out of the center's services. Because of the lack of trained human resources in the country, I have no options except the center-based services without any charge, whether it is sufficient or not.

Lack of support from the Government: All the participants complained that the government does not offer due consideration for autism care and treatment. As a result, the participants stated, there is no policy for autism in Ethiopia, no government-based autism centers, awareness-raising programs, and/or statistics on how many people are affected. The

report based on the data revealed no government services specifically designed for children with autism and their parents. In explaining the lack of support from the government, Parent #12 stated: *“Despite our grave needs, we don't have any kind of support from the government. We have health, educational and financial needs. But I don't know why it is not felt by the government.”* A key informant from the management of Nehemiah Autism Center desolately elaborated the lack of concern from the governments:

Well, there is nothing designed specifically for autism. Sadly, the government is not offering services for the parents, children, and the centers. Look, there is no autism policy, no government special schools, and other government-initiated programs. For our center, it has provided the license (permission to establish the center) and we would send quarters, six months and annual reports. Then, they would come and make supervision. ...We have asked for a piece of land to make the center free of costly house rent and we didn't get a response for the last seven years. I think, let alone providing financial and material supports, at least the government should encourage these kinds of centers by freeing us from water, electricity, telecommunications, and internet service bills. I don't think the government has given due concern for the issue.

Inaccessibility of the physical environment and different services was also raised by a key informant from Joy Autism Center as:

The physical environments of the facilities and services in this country are not comfortable for people with disabilities. The buildings, roads, schools, toilets, and hospitals are not comfortable and specially designed for people with disabilities. ...let alone others, to import toys and specially designed materials for the children from abroad, which we could not find in the local market, the tax rate is so high and we are unable to import, which in reality has to be free of any charge. As a result, our center is forced to have only the most basic and necessary equipment. So, the government has to do more in this regard.

Weak partnership and collaboration among the stakeholders: After the diagnosis, parents complained about the lack of communication between agencies and the complicated health care system, such as repeated costly and time-intensive doctor visits. Usually, programming related to intervention for autism demands the involvement of several key stakeholders that have a stake in influencing the life of the children and parents. This includes the child's family, schools, other experts in the fields, and community agencies that may assist parents in accessing supports and services needed by children with autism. Except for the partnerships between the parents and centers, the collaboration among the stakeholders is very weak.

Working in coordination with parents was emphasized as a pillar in determining the effectiveness of the teaching and learning process in both centers. All the key informants agree that the level of engagement by the parent influences the pace and direction of skill acquisition by autistic children. In speaking about the partnership, a key informant from Joy Autism Center said: *"We are closely working with the donors, parents as well as family members that spend much time with the children... Unless we involve them, all of our efforts would be a fruitless exercise."* Building on this, a teacher from the Nehemiah Autism Center said, *"As parental cooperation and level of engagement is a criterion to accept the children as well as to determine the continuity of the service. If parents are not willing to be engaged, we do not accept the children at the center."*

As an area of improvement, there is poor integration between the health care and education sectors. The key informants from Zewditu Memorial Hospital indicated that *"...like the developed countries of the world, 24 months are enough for the identification of ASD by health care providers. Early identification is a key to early intervention, which has shown to have a significantly positive effect on long-term outcomes for children with ASD. Early intervention can make a significant difference in improving physical, cognitive and social*

development for children with ASD. However, due to the absence of awareness and good linkage with health facilities, the opportunity for providing early education is I can say missing in this country.” Generally, the lack of good partnerships and collaboration has resulted in a low level of awareness among the community, lack of policy, good intervention strategies, and resources for the children and their parents.

To sum up, Joy is the first autism center established in 2002, and Nehemiah was established later in 2011 G.C. The supports provided by both centers are similar. Both centers provide psychosocial services for the parents (in the form of counseling, training, and monthly parental support group meetings). Children with autism are also provided with educational, communication, social, and self-help skill training, transportation, and lunch services free of charge. In addition, both centers have a program of helping the destitute women in abject poverty by providing training and initial seed money for the parents to participate in income-generating activities. In an attempt to offer services, the physical environment of the centers and communication between parents and teachers are stated as strengths of the centers’ services. On the other hand, lack of resources (financial and lack of trained human power), and partnership and collaboration among the stakeholders, and lack of support from the government are claimed to be the challenges of both centers.

Finally, the cumulative effects of the (psychological, social or financial) challenges were exhaustive for parents. Hence, having efficient and effective support systems was crucial for the parents of a child with autism in reducing the challenges of parenting the children. The data revealed the experiences of parents with informal support (including the support of the spouse, friends, relatives, neighbors, religious leaders, and members of the community) and formal support (services by the centers). Thus, the support (whether formal or informal) is a key factor in motivating the parents and reducing their burdens of caring for their autistic children.

4.6. Positive Experiences of Parents and Expectations about the Future of a Child with ASD

4.6.1. Positive Experiences of Parents of a Child with ASD

“Having a Child with an ASD is not all bad” (Weastell, 2017, p. 56).

Parents’ response to the study was courageous in both their willingness to share the difficult experiences and enduring efforts to overcome the significant barriers in raising their children to the best of their ability. Yet despite their challenges, as an emergent theme, the parents also shared some of their positive experiences. Hence, this study underscores that parenting an autistic child can be difficult and at the same time, rewarding. Astonishingly, tears were a common experience in most participants of this study. According to Glass (2001), because of the burdens and the challenges, tears are a normal part of the conversation involving the parents of autistic children. They are experiencing the reality of life on the two tips of the pendulum. They experience joy and sorrow from the same situation. During the interviews, while tears were shed many moments of laughter were also shared. The positive experiences were presented under the subthemes: positive emotions (love and gratitude), positive engagements (connection with others and opportunities), and positive spiritual developments.

Positive Emotions: The spontaneous responses to question about the positive aspects of parenting a child with autism by the majority started with the phrase it is ‘not easy, hard, challenging, difficult, demanding, and tough.’ However, spending a bit more time listening to their experiences, we were likely to hear about intensified “positive emotions” which is expressed in terms of ‘love’ and ‘gratitude.’ The love for her child and personal cost she has paid

is a strong motivator for parent #3, “...*he is a very precious boy for whom I lost everything in my life; I really love him.*”

Gratitude was common in participant quotes and the most commonly identified positive emotion by participants. This gratitude extended from the presence of the child to gratitude for what the parent has gained. Comparing her daughter’s situation to others, parent #11 expressed her gratitude as: “... *I thank God, looking at the situation of other parents; the behavior of my child is better and manageable.*”

Positive Engagements: Common positive engagements spoken by parents are organized under the subthemes of connection with others and opportunities. **Connection with others:** In contrast to findings under the subtheme “interpersonal loss” described previously, very few participants indicated that the experience benefitted their relationship with their partner. For instance: *My wife and I have been pretty strong through this. You know, it makes our relationship intact. We care for one another, and I think it made us stronger* (Parent #4). For one participant, it was used as a means of proving a true friend that endures through the worst times.

This situation has helped me to know my true friends in life. Whenever I go through the worst times, I have identified who is always there and didn’t fade away (Parent #12).

Opportunity: For a few participants, parenting a child with ASD has brought unique opportunities in their lives. All parents indicated that they know more about ASD and for a few participants’ opportunities to engage in new interests and altering their career paths have materialized. When speaking about the understanding and the knowledge they gained about ASD, one participant noted: “*I learned a lot about autism and its challenge on the victim and family members*” (Parent #11).

While the above participant noted a change in his/her understanding, a key informant from the Joy Autism Center, as well as participant #8 indicated a more extensive change, in that, they used their experience with ASD to inspire their career:

...But for me, it has brought an opportunity to establish the center, hire people, and above all it helped my child and other children in this situation. You see, I don't even think this will be my career trajectory. Now, I am the founder and manager of the center. If autism would not happen to my child and had not come into my life, I would not be working on this job and the way I am doing (a key informant from Joy Autism Center).

Earlier before my child's diagnosis, I was unemployed and just a housewife. Now, I am employed as a caregiver in this center because of my child. It has opened a door for my employment (Parent #8).

Positive Spiritual Development: The participants also discussed the positive qualities or skills that might develop as a byproduct of raising a child with ASD. Parent #1 explained her patience and self-regulation skills have grown after the diagnosis of her son with ASD:

From the very beginning, I believe God has provided me this child with a purpose... What I came to know through my entire journey is I think my God wants to teach me something critical in life, 'patience, and patience!' Now, I could say I am very calm and more tolerant of different situations happening in my life. I am thinking it is God's way of teaching me patience.

I have grown more in my faith. I have grown spiritually. When I feel stressed, I will pray to my God and believe that God is with me each day to ensure my children's needs and mine are met (Parent #5).

Parent #6 also reported an increase in her ability of planning and problem-solving skills. *... I think it teaches you to plan and prioritize things starting from daily routines. ...It also gives me problem-solving skills. For instance, if a melt-down or troublesome behavior occurs, I would try different options to avoid those unpleasant situations or triggering events.*

4.6.2. Parents' Expectation about the Future Lives of their Children with ASD

Respondents were asked about their expectations for future career of their children with ASD. In response, most of the respondents explained that they aspire for their children to be literate in reading and writing skills and to develop good communication skills through improving the fluency and quality of their language. Furthermore, most respondents believed that their children with autism would overcome barriers and become capable of functional independent living and being integrated into the life of local communities. Three respondents expect their children's cure or healing (through supernatural power) and lead their 'normal' life. These aspirations are very similar to reports of a study by Helen (2016).

4.7. Advice for other Parents of a child newly diagnosed with ASD

The participants were asked about the advice they would give to other parents of a child newly diagnosed with ASD. All participants' responses were positive and provided to inspire others. Some of the participants felt it would be important to advise other parents to have hope for a better future; thinking their children's situations would improve and change. Parent #9 stressed the importance of advising hope and faith (believing in God): *"I would tell there is hope. Hoping and believing God could change. So, I recommend praying, having hope and faith would be vital to see a change in their life."* Similarly, recognizing the long and tiresome journey, parent #4 suggested the idea of imparting hope to the parents of a newly diagnosed child:

I would let them have hope. I know and feel like it is a very difficult and long journey. From my experience, I would tell if they work hard, the child's and their situations will improve. Advising and thinking in this way would be helpful.

Some of the participants proposed telling others to accept, and to have tolerance and patience upon their journey. Parent #12 offered: *“I would say accept it and learn to live with it. Though I was challenged to accept and spent in a grieving process, I would say take the time and accept it. I think it was after acceptance that you can say oh! I have to help and provide support.”* In response to what she would advise other parents, parent #6 said:

I can say the parents have to be patient and persistent. I am not denying it is tough but the parents’ patience, tolerance, and perseverance would help them to control their life (emotions), and make fruitful, good decisions...

In addition, some would advise other parents that they have to be their child’s advocate and would stress the importance of obtaining services for their child, possibly through reflecting on their own experiences and desires for their children. For example, parent #1 said:

I advise parents with a newly diagnosed child not to stay in denial. Get out of denial and just start thinking about how you’re going to help your child. ...the other is to advocate for your child. Be the advocate. Don’t expect somebody to do it. You have to do it. Look for support from the organizations and get it. One more, offer love to your child!

Generally, considering their experiences, mistakes and what went wrong in their lives, the parents offered advice they think to be valuable for other parents with a newly diagnosed child as, hoping for improvement, prayer, faith, acceptance, patience, perseverance, advocacy, and finally to offer love, care, and support for their children.

4.8. Summary of the Chapter

This chapter provided a qualitative description of the study setting, socio-demographic characteristics of the participants, and descriptions of the narrative data. Through thematic data analysis, six major themes emerged: (a) parents’ awareness, perceptions, and reactions to the

diagnosis of autism, (b) challenges of autism for parents, (c) coping mechanisms, (d) supports, (e) positive experiences of parents and expectations about the future of their children, and (f) advice for parents of newly diagnosed children were identified.

On their journeys with autism, almost all participants felt overwhelmed by the challenges that come along with autism. To cope with the disorder, the parents employed different coping mechanisms (that could be categorized into positive and negative strategies), and the supports (whether formal or informal) have an essential implication for the welfare and well-being of the parents. Finally, under each theme, endeavors were made to highlight the individual and collective essences or meanings of parenting a child with ASD in Addis Ababa, Ethiopia. In the next chapter, the results of the quantitative data will be presented.

CHAPTER FIVE

5. Results of the Quantitative Data

5.1. Data Analysis

Quantitative data were collected to determine the levels of stress, stigma, and financial challenges; the most used coping mechanisms, and to examine whether the coping strategies mediate the relationship between stigma and stress in parents of children with autism. The data collected through structured questionnaires were analyzed using IBM SPSS (Version 26) and AMOS (Version 23) for Windows. AMOS is the most commonly used software program for SEM analysis, user-friendly, and relatively easy to specify models compared to other software programs such as LISREL, Mplus, and EQS (Garson, 2015). Accordingly, the collected data were cleaned and checked for completeness and then coded and entered into Statistical Package for Social Sciences (SPSS) software. To describe the data, both descriptive and inferential statistics were computed and presented in tables, bar graphs, and charts. Descriptive statistics, such as percentages, frequency distributions, means, standard deviations, minimum and maximum scores, and correlation analyses were used to summarize, observe and provide an overall picture of the data. According to Aron, Aron, and Coups (2008), descriptive statistics are used to review and present the data collected from the respondents. Inferential statistics (specifically, Structural Equation Models (SEM) were used to draw conclusions on the relationship between challenges (stress and stigma) and coping mechanisms of parents of a child with ASD. The Path/Structural Equation Models were computed to test the mediating role of coping strategy between stigma and stress. To examine the model fit of the path/SEM models, chi-square goodness of fit, Comparative Fit Index (CFI), Goodness of Fit Index (GFI), Normed Fit Index (NFI), Root Mean Square Residual (RSMR), and Root Mean Square Error of

Approximation (RMSEA) were used. Structural equation modeling was conducted using the IBM SPSS-AMOS program and in all cases, $p < .05$ (2-tailed) was considered significant.

5.2. Preliminary Analysis

A preliminary analysis was conducted to check for the assumptions of regression before performing analyses. Accordingly, assumptions to be checked included: (a) **Linearity**: the relationship between each of the independent variables and the dependent variable is linear, (b) **Homoscedasticity**: homogeneity of variance of the residuals, (c) **Normality**: the data are normally distributed, (d) **Multicollinearity**: there are no (low) multicollinearity, and (e) **Outliers**: there are no (little) outliers (Morgan, Leech, Gloeckner, & Barrett, 2007). Detailed reviews of the assumptions were screened.

Linearity: Independent variables collectively are assumed to be linearly related to the dependent variable in multiple regressions, and each independent variable is assumed to be linearly related to the dependent variable (Keith, 2006). The assumption of linearity states that the relation between the independent variable (IV) and the dependent variable (DV) must be linear. To assess this assumption, the data were examined graphically using a scatter plot with a best-fitting line. This process assures that the data do not follow a quadratic or cubic trajectory. In addition, residuals and the predicted values were plotted to assess the linearity of the relations between the variables. Data were visually examined using a probability-probability (P-P plot) and/or scatter plots of residuals. A scatter plot of standardized residuals against standardized predicted values was generated in SPSS. All relationships appeared linear; there was no curvilinear pattern, data points were randomly and evenly dispersed around the estimates or the

scatter cloud was around the horizontal line of zero. Therefore, the assumption of linearity of variance was not violated.

Homoscedasticity: The assumption of homoscedasticity refers to the variance of the residuals being constant across all values of the IV (Field, 2009). According to the assumption of homoscedasticity, residuals are equal for all values of the predicted dependent variable. Violation of this assumption does not affect the regression coefficients but does affect statistical significance (Cohen, Cohen, West, & Aiken, 2003; Keith, 2006). The assumption of homoscedasticity of residuals (equal error variances) was assessed through the examination of a scatter plot between the regression standardized residuals and predicted values. From the visual inspection of the scatter plot, the data showed a random pattern and appeared evenly dispersed at all levels of the best fitting line, indicating the assumption of homogeneity of variance was met (Stevens, 2009).

Normality: The assumption of normality states that the errors in the estimation of the outcome variable are normally distributed. As such, the distribution of residuals within the data should follow a normal distribution (Field, 2009). The assumption of normality was assessed through the examination of the visually inspected histogram for each variable with a superimposed normal curve and a normal P-P plot of the residuals.

The histogram of the residuals appeared to be normally distributed in a bell-shaped curve and the P-P plot displayed the z-scores plotted closely along the diagonal line. It was verified that residual errors were normally distributed with their values of residuals approximating a normal curve (Keith, 2006) and the data followed the normality line, indicating the assumption was met (Stevens, 2009).

Multicollinearity: Multicollinearity occurs when there is high covariance between two predictor variables (Field, 2009). Multicollinearity was assessed through correlational analyses. No predictor values were highly correlated with one another as such, the assumption of multicollinearity was not violated (Field, 2009). The absence of multicollinearity was also assured through examination of the Variance Inflation Factor (VIF) scores. The VIFs ranged from 1.10 to 1.37, which were lower than 10, and suggested that multicollinearity was not a serious cause of concern (Cohen et al., 2003). No score approached 10, the threshold suggested by Stevens (2009), indicating the assumption was met.

Outliers: Outliers were defined as being data points with a standardized Z score above 3.29 (Tabachnick & Fidell, 2013). The presence of significant outliers was checked by the examination of standardized values. Standardized values were created for each subscale score, and cases were examined for values beyond ± 3.29 standard deviations from the mean (Tabachnick & Fidell, 2013). As none of the outliers had a Z score greater than 3.00, and no notable influence on the difference between the original mean to the trimmed mean, all cases were retained. Finally, the data were assessed to check for the assumptions of multiple regressions and no violations of the assumptions of linearity, homoscedasticity, normality, multicollinearity, and outliers were observed. After all these assumptions were examined, analysis was performed to answer the research questions.

5.3. Reliability Test Statistics

Table 2: Reliability Test Statistics

Variables	Subscales	# of Items	Cronbach Alpha Level
Parenting Stress Index-Short form	Parental Distress (PD)	12	.902
	Parent-Child Dysfunctional Interaction (P-CDI)	12	.840
	Difficult Child (DC)	12	.843
	Total Stress score	36	.916
Stigma (FIS-SS)	Perceived Stigma level	14	.882
F- COPEs	Seeking Spiritual Support	4	.874
	Reframing	8	.888
	Mobilizing Family	4	.897
	Passive Appraisal	5	.917
	Acquiring Social Support	9	.805
	Total F-COPES score	30	.824
Informal social support	Informal support kinship	3	.850
	Informal support spouse	2	.825
	Informal support	6	.801
Formal social support	Programs/Organizations	4	.801
	Professional Services	4	.913
	Total Social Support	19	.760

Cronbach's Alpha test was used to assess the reliability of the instrument, and Cronbach's alpha levels greater than 0.70 are considered acceptable. The internal consistency of each category with subscales and respective items are shown in Table 2. The internal consistencies of participant responses in this study were acceptable for each subscale (i.e., above 80% Cronbach alpha levels were reported except for social support, 76%). Therefore, it denotes a higher level of indicator reliability.

5.4. The Concept of Structural Equation Modeling (SEM)

The structural equation model is a flexible, comprehensive model that specifies the pattern of relationships among independent and dependent variables, either observed or latent (Ho, 2006). The SEM model has two components: the measurement model and the structural model. A measurement model is used for defining the relations between observed and unobserved variables, whereas a structural model is employed to examine the relations among latent variables in a proposed model (Byrne, 2016).

In SEM, a variable is either exogenous or endogenous. An exogenous variable is the one that has a path or arrows pointing outward and none leading to it while an endogenous variable has at least one path leading to it and represents the effect variable (Wong, 2013). In the current study, the stigma for example is an exogenous variable, and stress is an endogenous variable. SEM was conducted to determine the association between the predictor variable (stigma) and outcome variables (stress). The mediation through path SEM analysis was conducted to examine the potential mediating effects of coping mechanisms in the association between stigma and stress outcome.

Why SEM is used in this study? One of the most important reasons for the widespread use of SEM is to test direct and indirect relationships among latent variables in a single model (Civelek, 2018). SEM was found to be a convenient method in the current study due to: First, SEM can estimate and test the relationships among constructs (Kline, 2005). Second, SEM can be used when the researchers' prime objective is prediction (Wong, 2013). The main objective of applying structural modeling in research is the explanation and prediction of target constructs (Hair, Black, Babin, & Anderson, 2010). Using this approach, one can simultaneously consider both the direct and indirect effects of the variables.

5.5. Statistical Analyses

5.5.1. Descriptive Analyses

Descriptive statistics including minimum and maximum scores, mean, and standard deviations were conducted to summarize the data from the questionnaire. Accordingly, results from descriptive analyses were compiled to describe the socio-demographic characteristics of the participants to ascertain information about the distribution, central tendency, and variability of the variables. A descriptive statistical analysis was conducted to obtain the parental characteristics and their relationship with the dependent variable of the study (stress).

5.5.1.1. Socio-demographic Characteristics of the Survey Respondents and its relationship with a Stress

Table 3: Stress and Socio-demographic Characteristics of the Parents

Socio-demographic Variables		N=108	Percent	Mean	Std	t-Value /F-value	P-Value
Gender	Male	19	17.59	118.0	25.73	-1.227	0.223
	Female	89	82.41	124.46	19.69		
Religion	Orthodox	65	60.19	124.02	22.80	0.093	0.96
	Muslim	16	14.81	121.00	15.98		
	Protestant	25	23.15	122.92	19.87		
	Catholic	2	1.85	124.50	3.54		
Marital Status	Married/living with a partner	87	80.56	121.76	19.68	2.70*	0.035
	Divorced/Separated	3	2.78	143.00	17.69		
	Widowed	3	2.78	109.00	18.19		
	Single (Never married)	6	5.56	143.50	5.79		
Educational Level	No formal education	11	10.19	126.18	18.11	2.69*	0.035
	Primary	18	16.67	124.94	15.71		
	Secondary	35	32.41	126.71	17.87		
	Certificate	14	12.96	123.21	29.10		
	Diploma holder	11	10.19	123.27	22.89		
	B.A/BSC Degree and Above	19	17.59	114.00	23.50		
Employment Status	Employed	51	47.22	118.39	22.13	-2.37*	0.020
	Unemployed	57	52.78	127.74	18.83		
Relations to the Child	Mother	87	80.56	125.15	18.11	3.31*	0.041
	Father	18	16.67	118.94	26.14		
	Other relatives*	3	2.78	96.67	45.36		
Have the child conditions caused financial problems for family?	Yes	97	89.81	125.69	18.89	3.70*	.000
	No	11	10.19	102.45	26.70		

Other relatives*-grandparents

In this study, as demonstrated in the above table, 108 parents from the two service settings completed the questionnaire. Out of the 108 parents, 82.41% of respondents were females, while the rest were males 17.59%. There was no significant difference observed in parental stress between males and females. Religion was the other socio-demographic variable for parents; 60.19 % of the participants were Orthodox Christians, 23.15% were Protestant Christians, 14.81% were Muslims, and others (1.85%) were Catholic. Concerning the marital status of the participants, 80.56% of participants were married/living with a partner, 2.78% of were divorced/separated, 2.78% were widowed and 5.56% were Single (Never married). Significant parental stress differences were observed among marital statuses. There was a high mean stress score of Divorced/Separated and single parents. Thus, stress is very high among the unaccompanied. A significant difference in parental stress across their educational level was observed. Parents with B.A/BSC and above Degree holders have lower stress than parents with another educational status. Specifically, parents with no formal and secondary education experienced higher stress. Not surprisingly, unemployed parents (52.78%) had more stress than employed parents (47.22%).

Relationship to the child was also another demographic item in this study and the results show that 80.56% were mothers, 16.67 % were fathers, and the rest 2.78 % were other relatives. Mothers were more stressed than fathers. Finally, almost 90% of parents reported that the child's condition has a contribution to financial problems of their family.

Table 4: Descriptive Information of Parents' for Continuous Variables versus Parental stress Status

Demographic variables	N	Min.	Max.	Mean	Std.D	Correlation to stress
1. Parents Age	108	22	68	37.64	10.27	-.25**
2. Number of children	108	1	4	1.67	.897	.025
3. Percent of family's monthly income for autism care and treatment	108	1%	15%	6.36%	2.27%	.42**
4. Family's monthly income (in Ethiopian birr/ETB)	108	1000	9100	2741.23	1981.55	.020

** Correlation is significant at the 0.01 level (2-tailed).

The participants' ages ranged from 22-68 (M=37.64, SD=10.27). There was a significant correlation between parental stress and parents' age. This implies that when parents' age increases, their stress decreases (See Table 4). This may be due to the developed experience and adaptation through the years. Family monthly income ranged from 1000 birr to a maximum of 9100 ETB per month with a mean of 2741.23, (SD= 1981.55). From these monthly incomes, an estimated one to fifteen percent of their income (M=6.36, SD=2.27) went to autism care and treatment-related costs. As the percent of the family's monthly income for autism care and treatment increases, parental stress also increased. This may be due to financial constraints.

Table 5: Association between Child's Characteristics and Parental Stress

Demographic variables	N	Min.	Max.	Mean	Std.D	Correlation to stress	t-test
1. Age of the child living with autism	108	4	16	7.21	2.835	.019	-
2. Child's Age at diagnosis	108	3.9	11.20	5.61	1.78	-.046	-
3. Gender of child: Male	87	62.0	162.0	120.01	21.2	-	-3.53*
Female	21	100.0	154.0	137.05	12.61	-	-
4. Center: Joy Autism	62	62.0	145.0	119.98	22.12	-	-
Nehemiah Autism	46	85.0	162.0	127.83	18.41	-	-

* Significant at the 0.05 level

The age of the child living with autism ranged from 4 to 16 years ($M=7.21$, $SD=2.835$). The child's age at diagnosis ranged from 3.9 to 11.2 years ($M=5.61$, $SD=1.78$). These children were on average diagnosed at the age of 5.6 years. Child's age and child's age at diagnosis had no significant effect on parental stress. Looking at the children's gender, 80.55% ($N=87$) were male and 19.44% ($N=21$) were female. Parents of a female child with autism were more stressed than parents with male children with autism. Finally, as per the sample size, 62(57.4%) of the parents were obtaining services at Joy Autism Center and the rest 46(42.6%) were receiving services at Nehemiah Autism Center.

5.6. Challenges of Parents of Children with Autism

5.6.1. Levels of Parental Stress

5.6.1.1. Parenting Stress Subscales

The dependent variable as measured by the Parenting Stress Index had three subscales: the first, measuring the stress as a result of the child's condition or behavior (Difficult Child); the second measures stress as a result of parental condition (Parental Distress). Thirdly, parental and child attributes can interact and develop parenting stress (Parent-Child Dysfunctional Interactions). As indicated in the Table 6, the respondents "agree" that they experience the highest level of stress as a result of difficult child behavior ($M=53.54$, $SD=10.94$), followed by parent child-dysfunctional interaction ($M=53.30$, $SD=8.83$) and parental distress ($M=41.61$, $SD=9.47$). The total PSI-SF scores reflected a high level of stress for 61(56.48%) of the parents participating in this study.

Table 6: Parenting Stress Subscales

S.No	Factors	N	Mean (Avg. Score)	Std.	Minimum	Maximum
1	Difficult Child	108	53.54 (2.44)	10.94048	27.00	70.00
2	Parental Distress	108	41.61 (1.19)	9.47447	14.00	59.00
3	Parent-Child Dysfunctional Interaction	108	53.29 (2.37)	8.82617	28.00	71.00

5.6.1.2. Correlational Analysis among Parenting Stress Index-Short Form Subscales

Correlation coefficients (r) indicate the magnitude and direction of the linear relationship between two variables on an ordinal scale (Hinkle, Wiersma, & Jurs, 2003). We ran a correlation analysis to examine if there is a relationship among the parenting stress subscales. Pearson's correlation was carried out to look for association between the variables parenting stress subscales (difficult child, parental distress, and parent-child dysfunctional interaction). As indicated in Table 7, Difficult Child is positively and strongly correlated with parent-child dysfunctional interaction ($r=0.494$, $p<0.01$). Difficult Child is also positively and strongly correlated with parent distress ($r=0.472$, $p<0.01$). Finally, parent-child dysfunctional interaction was also strongly correlated with parent distress ($r=0.295$, $p<0.01$). All associations are statistically significant at a 99% confidence interval (See Table 7).

Table 7: Correlation Matrix among Parenting Stress Index-Short Form Subscales

			DC	PD	PCD
Pearson's Correlation	Difficult Child	Correlation Coefficient	1.000		
		Sig. (2-tailed)	.		
		N	100		
	Parental Distress	Correlation Coefficient	.472**	1.000	
		Sig. (2-tailed)	.000	.	
		N	100	108	
	Parent-Child Dysfunctional Interaction	Correlation Coefficient	.494**	.295**	1.000
		Sig. (2-tailed)	.000	.002	.
		N	98	106	106
** Correlation is significant at the 0.01 level (2-tailed).					

5.6.1.3. Parental Stress versus Social Support

Table 8: Pearson Correlation of Total Parental Stress and Types of Social Support

	Total parental stress	Informal social support	Formal social support
Total parental stress	1		
Informal social support	-.458**	1	
Formal social support	-.147	.146	1

** . Correlation is significant at the 0.01 level

A Pearson correlation analysis was employed to examine the association between parenting stress and social support. As indicated in the Table 8, parental stress is negatively and strongly correlated with informal support ($r = -.458$, $p < 0.01$). There is an inverse relationship or when one increases the other decreases and that was statistically significant at a 99% confidence interval. Formal social support had a weak (insignificant) relationship with parental stress.

5.6.2. Levels of Stigma

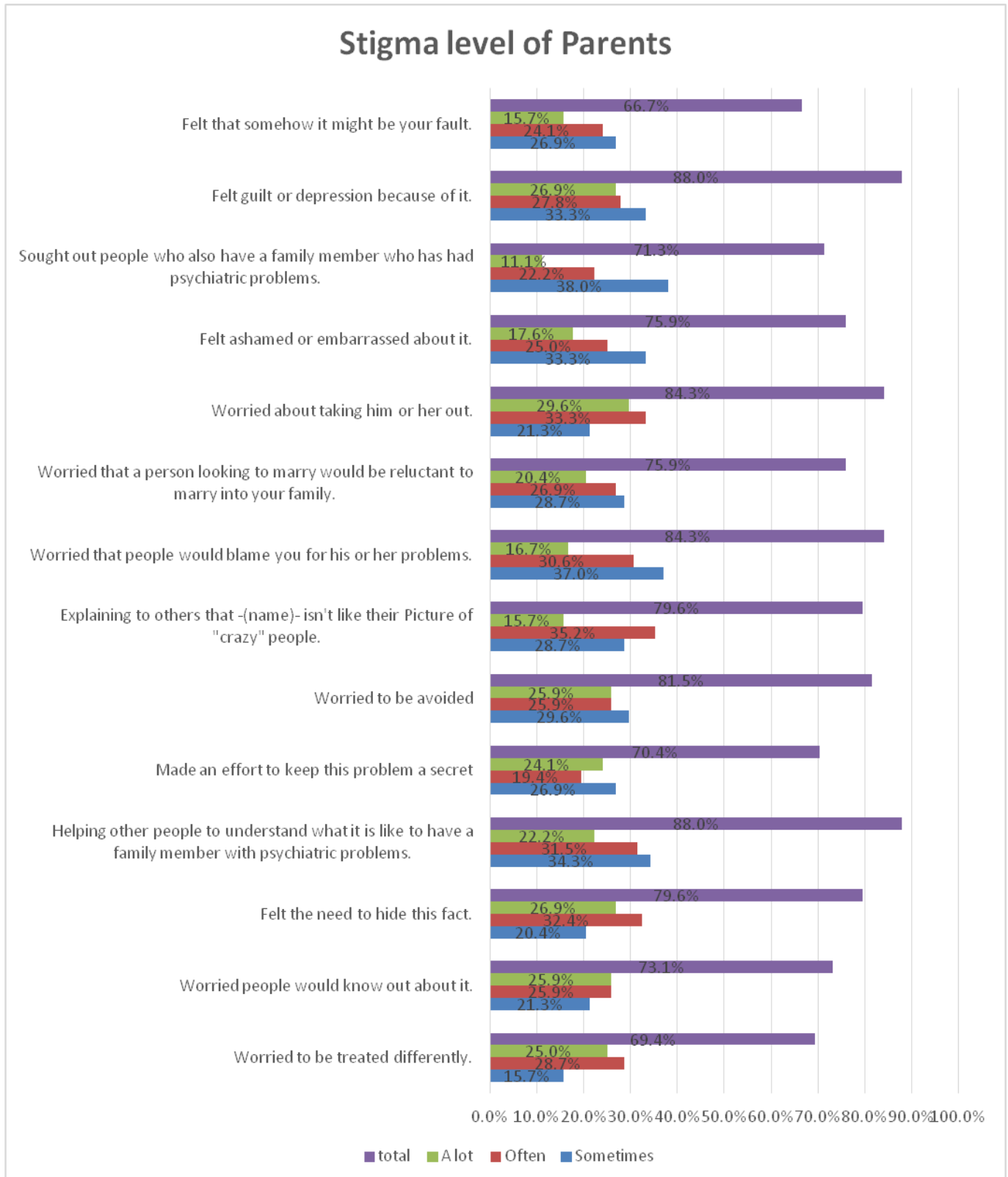
The presence of perceived stigma was defined by the respondent's score of at least one positive item on the fourteen FIS items. Overall, the prevalence of perceived stigma was found to be 77.7%. Out of this figure nearly half 49.47% of respondents perceived stigma often or a lot. Parents of children with autism reported experiencing stigma on many items of the adapted FIS (see Figure 9). Regarding the proportion of perceived stigma of each item, 95 out of 108 participants (88.7%) indicated they felt grief or depression 'sometimes', 'often' or 'a lot' because of the autism. Likewise, many sought out other parents also have a child with similar problems ($n = 77$; 71.3%) and felt that somehow it might be their fault ($n = 72$; 66.7%). Other experiences of caregivers included worrying about taking him or her out ($n = 91$; 84.2%), explaining to others

that (your child) isn't like their picture of "crazy" people (n=86; 79.6%), and worrying about being treated differently (n=75; 69.4%).

Table 9: Stigma Scale level (n=108)

Statements	Not at all	Sometimes	Often	A lot
Worried to be treated differently	33(30.6%)	17(15.7%)	31(28.7%)	27(25.0%)
Worried people would know out about it	29(26.9%)	23(21.3%)	28(25.9%)	28(25.9%)
Felt the need to hide this fact	22(20.4%)	22(20.4%)	35(32.4%)	29(26.9%)
Helping other people to understand what it is like to have a family member with psychiatric problems	13(12.0%)	37(34.3%)	34(31.5%)	24(22.2%)
Made an effort to keep this problem a secret	32(29.6%)	29(26.9%)	21(19.4%)	26(24.1%)
Worried to be avoided	20(18.5%)	32(29.6%)	28(25.9%)	28(25.9%)
Explaining to others that -(name)- isn't like their Picture of "crazy" people	22(20.4%)	31(28.7%)	38(35.2%)	17(15.7%)
Worried that people would blame you for his or her problems	17(15.7%)	40(37.0%)	33(30.6%)	18(16.7%)
Worried that a person looking to marry would be reluctant to marry into your family	26(24.1%)	31(28.7%)	29(26.9%)	22(20.4%)
Worried about taking him or her out	17(15.7%)	23(21.3%)	36(33.3%)	32(29.6%)
Felt ashamed or embarrassed about it	26(24.1%)	36(33.3%)	27(25.0%)	19(17.6%)
Sought out people who also have a family member who has had psychiatric problems	31(28.7%)	41(38.0%)	24(22.2%)	12(11.1%)
Felt guilt or depression because of it	13(12.0%)	36(33.3%)	30(27.8%)	29(26.9%)
Felt that somehow it might be your fault	36(33.3%)	29(26.9%)	26(24.1%)	17(15.7%)
Total percent average of each		28.24%	27.78%	21.69%
Total percent average		77.71%		

Figure 9: Pattern of positive responses on the Family Interview Schedule among Parents of Children with ASD



5.6.3. Level of Financial Constraints

Table 10: Participants response about whether child conditions caused financial problems (n=108)

Responses	Has the child conditions caused financial problems for your family?	
	Frequency	Percent
Yes	97	89.8
No	11	10.2

Most of the participants (n=97; 89.8%) indicated experiencing financial problems as a result of autism as shown in Table 10. Furthermore, for the covariate determination analyses, the financial situation was categorized into four levels by combining “routinely or occasionally unable to purchase sufficient food or other basic necessities” (n=53; 55.8%), so that all the categories would be similar in terms of sample size. The other three categories were “sometimes worried about having enough money for the necessities” (n=28; 29.5%), “never worried about having enough money for the necessities” (n=10; 10.5%), and “have more than enough money for necessities and some luxuries” (n=4; 4.2%).

Table 11: Chi-Square Analysis of current financial situation (n=108)

Financial Situations	Has the child conditions caused financial problems for your family?		Total	Pearson Chi-Square	DF	P-value
	Yes	No				
	Count (%)	Count (%)				
Routinely or Occasionally unable to purchase sufficient food or other basic necessities	53(55.8)	2(20.0)	55(52.4)	8.9	3	.031
Sometimes worried about having enough money for the necessities	28(29.5)	4(40.0)	32(30.5)			
Never worry about having enough money for the necessities	10(10.5)	4(40)	14(13.3)			
Have more than enough money for necessities and some luxuries	4(4.2)	0(0.0)	4(3.8)			

Chi-square analyses showed a significant association between child conditions and financial problems (Pearson Chi-Square/ χ^2 = 8.9, $p < 0.05$). These data suggest that the respondents who reported that “the child conditions have caused financial problems for family” were more (55.8%) likely to report being routinely or occasionally unable to purchase sufficient food or other basic necessities, compared to respondents who said that “the child conditions has not caused financial problems for family”. Additionally, the respondents who reported “the child conditions have caused financial problems for family appears to have had fewer participants who reported having more than enough money for necessities and some luxuries, compared to the other.” Thus, the child’s condition was perceived to have a significant effect on the family’s financial situation (see Table 11).

5.6.4. Summary on the Challenges faced by the Participants

To answer the question “What proportion of parents reported stress, stigma and financial challenges?” the following table demonstrates that the most common challenge reported by parents was financial constraints (89.8%), followed by stigma (77.71%), and stress (56.5%) as depicted in Table 12.

Table 12: Challenges faced by the participants

Challenges Faced	Frequency	Percentage
Financial constraint	97	89.8%
Stigma	84	77.71%
Stress	61	56.5%

5.7. Coping Mechanisms

5.7.1. Type of Coping Mechanisms used by the Parents of Children with Autism

Coping mechanisms, the mediating variable, measured by the Family Crisis Oriented Personal Evaluation Scales (F-COPES), had five subscales: seeking spiritual support, reframing, mobilizing family, passive appraisal, and acquiring social support. Respondents agreed that seeking spiritual support was the most commonly used coping strategy ($M=16.08$, $SD=2.99$), followed by reframing ($M=24.65$, $SD=6.74$), mobilizing family ($M=14.28$, $SD=3.94$), and passive appraisal ($M=14.65$, $SD=5.57$), with the lowest through acquiring social support ($M=36.44$, $SD=5.278$) as shown in Table 13.

Table 13: Type of Coping Mechanisms used by the participants (n=108)

	Mean	SD
1. Seeking Spiritual Support	16.08(4.78)	2.99
2. Reframing	24.65(4.16)	6.74
3. Mobilizing Family	14.28(2.57)	3.94
4. Passive Appraisal	14.65(1.79)	5.57
5. Acquiring Social Support	36.44(1.69)	5.278
Coping Mechanisms Total Score	106.62	12.28

5.8. The Mediating Role of Coping Mechanism on the Relationship between Stigma and Parental Stress

The relationships among variables stigma, coping strategy, and parental stress (based on the model seen in Figure 10) were examined using path analysis. This technique was chosen because of its capacity to simultaneously test causal processes based on an underlying theory or

model. Table 14 shows the direct and indirect effect of stigma on parental levels of stress among parents of children with autism.

Table 14: Path Coefficients for Parental Stress Level

Variable	Direct	Indirect	Total
Stigma	.563**	-.163**	.4**
Coping strategies	-.672**	-	-.672**

*. Path Coefficient is significant at the 0.05 level (2-tailed).

**. Path Coefficient is significant at the 0.01 level (2-tailed).

The model has explained the 58.5% variance in parental stress as fully reported in figure 10. It is estimated that the predictors (stigma and coping strategy) of parental stress explain 58.5 percent of its variance. The standardized total (direct and indirect) effect of stigma on parental stress was .400. That is, due to both direct (unmediated) and an indirect (mediated) effect of stigma on parental stress, when stigma goes up by 1 standard deviation, parental stress goes up by 0.4 standard deviations. The standardized total (direct and indirect) effect of stigma on parental stress was significantly different from zero at the 0.001 level ($p=.002$, two-tailed).

The standardized direct (unmediated) effect of stigma on parental stress is .563. That is, due to the direct (unmediated) effect of stigma on parental stress; when stigma goes up by 1 standard deviation, parental stress goes up by 0.563 standard deviations. This is in addition to any indirect (mediated) effect that stigma may have on parental stress. The direct (unmediated) effect of stigma on parental stress is significantly different from zero at the 0.001 level ($p=.002$ two-tailed). The standardized indirect (mediated) effect of stigma on parental stress was -.163. That is, due to the indirect (mediated) effect of stigma on parental stress, when stigma goes up by 1 standard deviation, parental stress goes down by 0.163 standard deviations when mediated by

coping strategy. The indirect (mediated) effect of stigma on parental stress is significantly different from zero at the 0.001 level ($p=.002$ two-tailed).

The standardized direct (unmediated) effect of coping strategy on parental stress was -.672. That is, due to the direct (unmediated) effect of coping strategy on parental stress, when coping strategy goes up by 1 standard deviation, parental stress goes down by 0.672 standard deviations. This is in addition to any indirect (mediated) effect that coping strategy may have on parental stress. The standardized direct (unmediated) effect of coping strategy on parental stress was significantly different from zero at the 0.001 level ($p=.003$ two-tailed).

5.9. Evaluations of Goodness-of-Fit (GOF) Measures

Table 15: Model Fit Indices for Structural Model

Fitting Index	χ^2	CFI	GFI	NFI	TLI	SRMR	RMSEA
Model Index	.64	.998	.991	.974	.962	.053	.027
Acceptable level	p-value > .05	$\geq .90$	$\geq .90$	$\geq .90$	$\geq .92$	$\leq .06$	$\leq .06$

The Goodness of fit statistics compares the fit between theory (the proposed model) and reality/data (Hair et al., 2010). The (GOF) measures how well the data fit or depart from the predicted model. Goodness-of-fit (GOF) assessment is very essential to make sure of the suitability between the theoretical model and the empirical data and permit the comparison of the efficacy of multiple competing models (Byrne, 2016). Generally, model fit indices (GOF indicators) can be classified into three major categories: absolute, incremental, and parsimony fit measures (Byrne, 2016; Hair et al., 2010; Ho, 2006; Kline, 2005).

(1) Absolute Fit Measures

Absolute Fit measures provide the most fundamental indicator of how well the proposed theory fits the data (McDonald and Ho, 2002). Measures included in this category are Chi-square (χ^2) test, Goodness of Fit (GFI), Root Mean Square Residual (RSMR), and Root Mean Square Error of Approximation (RMSEA).

To test the absolute fit measure, the chi-square measurement is the most preferred one. Chi-square is a test assessing the difference of significance between the matrix of implied variance and covariance, and empirical sample variance and covariance (Hu & Bentler, 1999). A non-significant χ^2 value ($p > .05$) indicates the good fit of the model with the sample data (Hair et al., 2010). Even though this statistical measure is the most prominent one to determine model fit, its over-sensitivity to sample size is pinpointed as a major drawback of the measure (Hu & Bentler, 1999). Chisquare (χ^2) the test of the measurement model for this study (0.64) demonstrated that it had a good fit to the model.

Goodness-of-Fit Index (GFI): GFI is the other absolute goodness-of-fit measure. GFI determines the relative extent of variance and covariance jointly explained by the model (Tabachnick & Fidell, 2013). GFI values range from 0 (showing bad fit) to 1 (showing perfect fit), where a value of .90 and greater is suggested as an indicator of good fit (Byrne, 2016; Kline, 2005). The GFI measure reflects the level of variance between the sample covariance matrix and the specified covariance matrix (Ho, 2006) and is also a common measure reported. A limitation of this measure, similar to chi-square is that it can be influenced by large sample sizes and can be inflated simply by specifying more parameters (Holmes-Smith, 2001). Kline (2005) claims that

the RMSE measure is more highly susceptible to model size than the sample size. In contrast, GFI is more sensitive to sample size than model size.

Root Mean Square Error of Approximation (RMSEA): The Root Mean Square Error of Approximation (RMSEA) is scaled as a badness-of-fit index where a value of zero indicates the best fit. RMSEA measures approximation error between the observed covariance and covariance of the hypothesized model (Meyers, Gamst, & Guorino, 2006). RMSEA takes into account the error of approximation in the population. It is a measure of discrepancy per degree of freedom and is representative of the goodness-of-fit when the proposed model is estimated in the population (Ho, 2006). According to Hu and Bentler (1999), RSMR and RMSEA values of less than .06 signify a good fit. In this study, the researcher has accepted the RSMEA result of .027 as a good fit based on the above cut of point.

(2) Incremental Fit Measures

Incremental fit measures assess the proportionate improvement in fit by comparing the generated model to possible baseline or null models estimated with the same data (Anderson & Garbing, 1988). The incremental fit measure includes Comparative Fit Index (CFI), Normed Fit Index (NFI), and Tucker-Lewis Index (TLI). Hu and Bentle (1999) suggested that CFI, GFI, NFI, and TLI values above 0.90 are generally interpreted as representing a good fit.

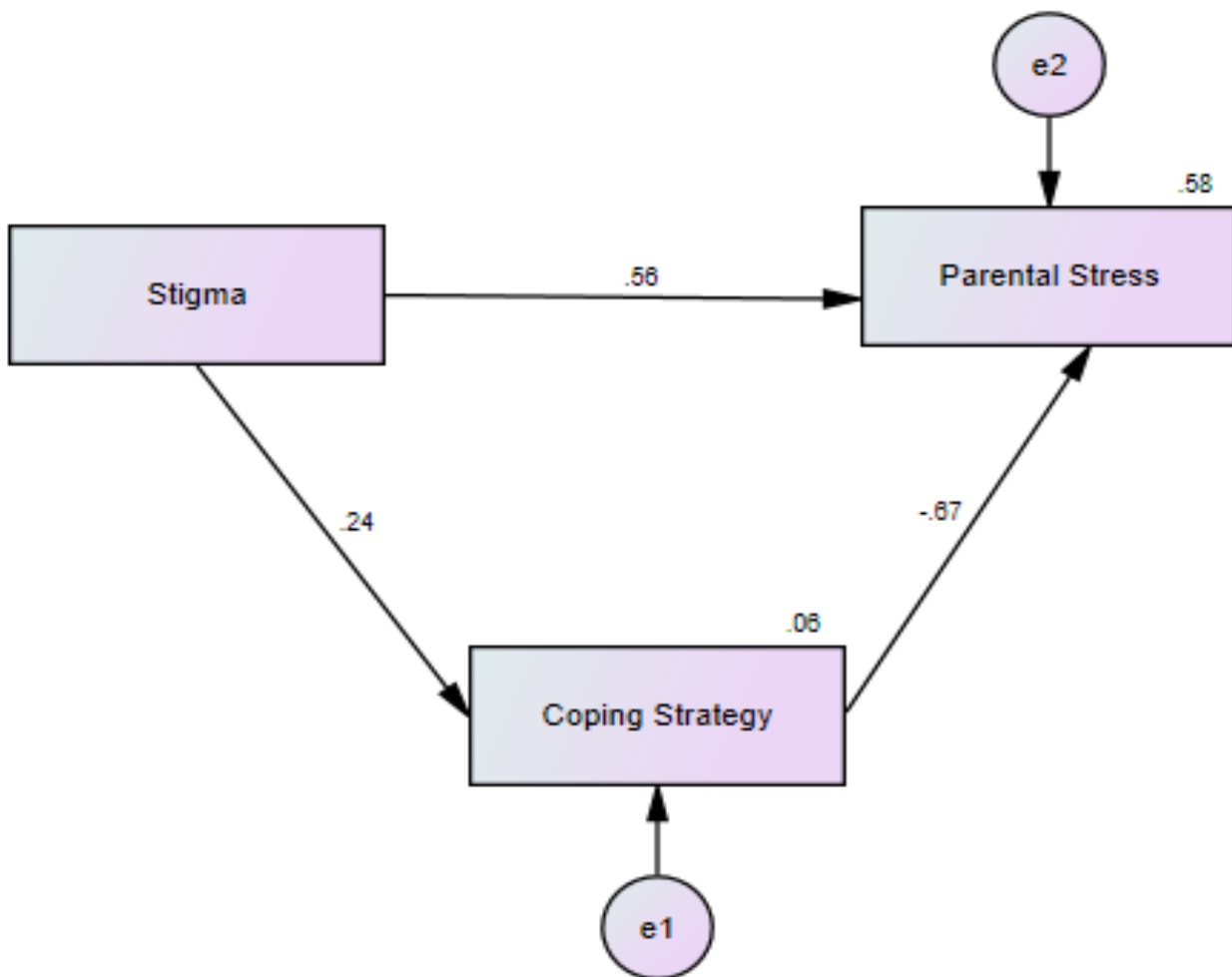
(3) Parsimonious Fit Measures

The third category of model fit indices is parsimonious fit indices. Parsimony fit measures evaluate the fit of the model in relation to the number of estimated coefficients required to achieve the level of fit (Hair et al., 2010). The normed chi-square (χ^2/df) is the commonest parsimonious fit measure used for evaluating the SEM model (Cangur & Ercan,

2015). The χ^2/df ratio values less than 3.0 have been suggested as acceptable values (Kline, 2005).

Generally, Table 15 confirmed that CFI= .998, GFI= .991, NFI= .974, TLI= .962, SRMR= .053, and RMSEA= .027, which falls in the acceptable range of the model fit based on the cut of point. Thus, results of fit indices for SEM indicated that the overall model had a good model fit and supported the acceptance of the model.

Figure 10: Model depicting the Mediating Role of Coping Mechanisms on the Relationship between Stigma and Parental Stress



CHAPTER SIX

6. DISCUSSION

This chapter discusses the findings presented in the previous chapters on the challenges, coping mechanisms, and supports for parents of a child with ASD. Based on the emergent themes and overall objectives of the study, the challenges, coping mechanisms, and supports for parents living with a child diagnosed with autism are compared against prior established knowledge and research findings. Hence, the major findings of the study that are identified in the previous chapters are discussed in light of the selected theoretical framework, reviewed literature, and related studies.

6.1. Discussion on the Socio-demographic Characteristics

Socio-demographic characteristics of the participants were generally consistent with studies of parents and children affected by autism (Pisula & Kossakowska, 2010; Rivard, Terroux, Parent-Boursier, & Mercier, 2014; Soltanifar et al., 2015), and mothers demonstrated a higher rate of participation in the study than fathers did. Boyd (2002) attributed higher response rates to mothers being primary caretakers of their children with autism. Likewise, Dokmanovic (2016) found that mothers were more involved in their child's day-to-day care.

More than half of the parents in our study were at primary or secondary educational levels, while in high-income countries, it has been reported that children with ASD had more educated parents than the general population (Zuckerman, Lindly, & Sinche, 2015). In several studies parents with lower education experience significantly more stress and have less access to services, and less knowledge of typical child development, which consequently leads to later diagnosis of ASD (Kogan et al., 2007).

The percentage of respondents reporting to be either “married” or “living with a domestic partner” was approximately 80% (Cheatham, 2016). Regarding the gender of respondents’ children, approximately three times as many respondents in the sample reported having a male child than a female child with autism. It has been well documented that a higher prevalence of ASD is found among male children, and data in our study are also similar; nearly 80 percent of children were boys (Christensen et al., 2016). In our study, the mean age for the final diagnosis of ASD was 5.61 years. A significant amount of evidence shows that a reliable and stable diagnosis of ASD can be made around the age of two years (Boorstein et al., 2008). Detection and explanation of symptoms can be significantly delayed by their parents and/or lack of good health infrastructure in the community (Werner, Dawson, Munson, & Osterling, 2005). This time lag from the occurrence of the first symptoms and the diagnosis may be due to lack of access to diagnostic or evaluation services (Cheatham, 2016). In standard practice in Ethiopia, there is no regular screening or proper prospective assessment of children at risk of developmental disorders, and detection of these problems often relies on parents’ initial suspects and concerns about their children’s development that led them to go to physicians and health centers.

6.2. Discussion on the Lack of Awareness, Perceptions, and Reactions to the Diagnoses of Autism

Before the diagnosis of their children, most of the participants in this study had no or little awareness of autism. Similar findings were seen in studies done in other African countries such as Kenya, which identified that lack of awareness and information as one of the problems in raising a child with autism spectrum disorder (Gona et al., 2016). Baba (2014) conducted a study in Nigeria that revealed the lack of understanding and awareness about autism in the community across different ethnic groups and economic classes. According to Rakib (2013), in Bangladesh,

1% of the children are estimated to be autistic; however, there is still a lack of understanding about autism among the general public, including parents.

Immediately after their children were diagnosed with ASD, most participants still did not fully understand what ASD entails. Lack of awareness is further mentioned in the way the parents perceived the problem. Almost all the parents had little awareness and knowledge about the developmental disorder except in some cases having heard the name. This is similar to the findings of Demissie (2015) in Ethiopia and other developing countries by Matenge (2012) in South Africa; and Gona et al. (2016) in Kenya. These studies have also shown that parents gave a mixture of biomedical and traditional explanations as the cause of the developmental disorder. This accorded with the findings of Tilahun et al. (2016) in Ethiopia, where parents gave explanations that were a mixture of biomedical and traditional explanations. They mostly gave the traditional way of explaining their child's neurodevelopmental disorder and continued to look for help in traditional and religious centers even after finding out about the child's case. This again corresponds with a study in South Africa that found parents kept looking for remedies even after knowing the child's diagnosis (Badu, 2015).

Regarding the etiology of autism, participants have attributed it to supernatural powers: being possessed by an evil spirit, evil eye, and people doing evil things to others or punishment for an individual's sin. This finding coincides with research done in Ethiopia that indicated awareness of the mental illness and developmental disorder is influenced by cultural and religious views of the community that associate autism with evil and supernatural forces (Alem et al., 1999; Shibrei, Spangeus, Henriksson, Negash, & Jacobsson, 2008). This view is supported by Cockerham's (1981) argument that says in most preliterate cultures people's source of

information about mental illness and developmental disorder is mainly based on the cultural and spiritual views of the society.

These spiritual and cultural beliefs about the child's symptomology are similar to the prevailing ideas held in Ghana (Anthony, 2009), Kenya (Gona et al., 2016), Taiwan (Shyu et al., 2010), and South Korea (Kim, 2012) that suggest divine power, punishment for one's wrongdoings, and evil spirits lead to the child's symptom development. However, different results were brought by Russell and Norwich's (2012) study in the UK, Altieri (2006) in the United States, and Shaked & Bilu's (2006) study in Israel in which the majority of parents reported physiological causes including labor complications, problematic infant immunization, genetic inheritance, and viral infection during pregnancy, a serious disease in the first year of life, head trauma and organic defect in the brain as causes for their children's developmental disability. Samadi and McConkey (2011) conducted a study in Iran and compared how sources of information differ between affluent and less affluent countries. For less affluent countries, the main source of information was found to be other parents in a similar situation while self-researching using books and websites were reported as the main source of information for parents in affluent countries. This contrary finding with the studies in the west (high-income countries) might be due to cultural differences and better access to trained professionals who can provide parents with sufficient information on the causes, behavioral manifestations, and interventions options for autism compared to ours.

In general, the awareness, perception, and treatment choice parents have are mainly influenced by the cultural, religious, and traditional practices that are predominant in the community. This argument is backed by the ecological perspective that argues people are influenced by the values, customs, attitudes, and laws of the culture in which they live (Smith, et

al., 2009). This study found that parents were commonly exposed to culturally transmitted fears and concerns that they may have done something wrong in the past to cause the disorder (e.g., spirit possession). Though the majority of parents did not believe in these traditional lay beliefs, they still described these societal perspectives as stigmatizing and impacting their well-being (Ilias, Liaw, Cornish, Park, & Golden, 2016). It is therefore plausible that the cultural beliefs of parental sins, and/or curses in the etiological understanding of ASD have to be averted through large-scale awareness-raising training and programs.

6.3. Discussion on Parents' Reactions to Diagnosis for Autism

The participants were asked questions on how they felt, responded, or reacted when they noticed their child's autism. It is reported that when parents heard the news for the first time that their children are autistic, they enter into shock, uncertainty, anger, denial, and guilt (Hong, Seltzer, & Greenberg, 2008). According to Durban et al.'s (2012) study in the Philippines, the majority (65.12%) of the parents were stressed and overwhelmed upon learning of their child's disability. The authors further elaborated that parents expressed being shocked, sad, and fearful of their child's fate especially if the child with developmental delay would outlive them. In this qualitative study, the parents described their reactions to diagnoses of autism, and it was found that almost all the participants displayed a range of emotions including despair, sadness, shock, confusion, sorrow, grief, and feelings of loss. This is very similar to reports from participants living in the U.S. (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009), France (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011), China (McCabe, 2008), Iran (Samadi, McConkey, & Kelly, 2012), Turkey (Bilgin & Kucuk, 2010), and South Africa (Badu, 2015) that found parents to have feelings of despair, sadness, or being overwhelmed upon first hearing of their children's diagnosis, along with a period of grief associated with those feelings. On the other hand, a couple

of parents reported a feeling of relief upon learning of their child's diagnosis, which is similar to respondents in the United Kingdom (Russell & Norwich, 2012) and France (Chamak et al., 2011).

6.4. Discussion on the Challenges of Autism for Parents

In the previous chapter, the challenges faced by parents of children living with autism were identified and presented in light of the specific objectives of the study. Autism compels parents to endure additional roles and tasks. This is because the behavioral problems the child with autism displayed (like physical aggression, damaging properties, and uncertainty) and the effect of the disorder (lack of self-care, inability to work, and social isolation) on the child create a new and additional role for the parents. Parents become burdened by providing more care than what is needed for a typically developing child of that age (Schene et al., 1998; Knudson & Coyle, 2002). In this subsection, the difficulties and burdens associated with having a child with autism that have been documented in reviewed literature were compared with and contrasted against the findings of this study. Therefore, the psychological, social, and financial challenges of raising children with autism are discussed in light of the theoretical perspectives and reviewed literature.

6.4.1. Discussion on the Psychological Challenges

In the preceding chapter, the parents revealed the psychological challenges they are enduring while raising their children. Accordingly, the parents described the stress and emotional disturbance they experienced. In their meta-synthesis of 14 studies on the lived experiences of parenting children with autism (Cocoran, Berry, and Hill, 2015) also reported: "Caring for a child with ASD is an emotionally taxing experience and parents reported intense negative

emotions” (p. 358). Dumas et al. (1991) found stress to be higher among parents of children with autism than parents of a child without autism. Consistent with previous studies (e.g., Hastings, 2008; Karst & Van Hecke, 2012; Kuhaneck et al., 2010), findings of the current study indicated 56% of the sample presented with high levels of stress.

The Severity of Parenting Stress: Parenting a child with ASD is a journey that begins with initial concerns of parents that something may not be “quite right” with their child. The parent receives a diagnosis for their child, begins a marathon of visits to professionals, and navigates through services and supports to obtain the most appropriate intervention for their child. Once initial treatments are started, future worries continue to arise as the child’s developmental trajectory changes and unfolds over time. Parental stress in this population is higher than in parents of typically developing children (Hastings et al., 2006). Thus, the findings of this study are consistent with previous studies (Bromley et al., 2004; Dumas et al., 1991; Erguner-Tekinalp & Akkok, 2004; Hastings, 2003; Hastings & Johnson, 2001; Koegel et al., 1992; Konstantareas & Papageorgiou, 2006; Lecavalier, Leone, & Wiltz, 2006; Lyons et al., 2010; Pisula & Kossakowska, 2010; Rivard et al., 2014; Soltanifar et al., 2015; Tomanik et al., 2004), that indicated parents of children diagnosed with ASD experience high levels of stress.

The factors that stress parents include the inability of children to express their feelings, the future life of their child, feelings of sorrow, and worry about who will take care of him or her if something happens to the parent. This is in line with the Autism Society’s (2011) categorization of factors that put parents in a stressful situation as a “child’s inability to express his/her own needs, taking child diagnosed with autism out of the community, the concern about the child’s future welfare, parents’ financial stress and feelings of grief” (as cited in Hartmann, 2012, p. 8). Heiman (2002) reported that parents of a child with autism experienced considerable

stress, as the child will bring uncountable problems related to growth, caring, management of developmental tasks, and the unclear prospect of the child.

Many of the studies of parental stress in families with ASD attribute the high levels of stress to the behavioral challenges that are often inherent to ASD (Sharpley & Bitsika, 1997). As a result, it was expected that parents would have higher scores on the difficult child (DC) subscale. Similarly, studies by Tomanik et al. (2004) have attributed the increased stress to behavioral characteristics associated with ASD and severity of symptoms (Konstantareas & Papageorgiou, 2006).

Parenting Stress, Child Characteristics, and Severity of Autism Symptoms: The severity of autism symptoms was also found to affect parenting stress among parents of children with ASD (Ilias et al., 2016; Lai et al., 2015; Lyons et al., 2010). Using a comparison group (parents of children with typical development) in a Singaporean sample, Lai and colleagues (2015) were able to show that parents of children with ASD (who were found to have more experience of difficult child behavior) had higher levels of parenting stress.

Conversely, the result of the current study is inconsistent with the below-stated studies regarding the stress and age of the child with autism. Although studies have found significant correlations between parental stress levels and the age of children with autism (Davis & Carter, 2008; Gray, 2002; Konstantareas & Homatidis, 1989), we found no statistically significant correlation between these variables.

According to Davis and Carter (2008), there is consistent association between child characteristics and parenting stress in parents of children with autism. Child symptom severity and child behavior problems have been the two predictive variables investigated most frequently

(Falk, Norris, & Quinn, 2014). Studies investigating the relationship between concurrent parental stress and child symptom severity (Ingersoll & Hambrick, 2011) as well as concurrent parental stress and behavior problems (Estes et al., 2013) have identified an association between these factors although they do not necessarily imply causality. Studies looking only at concurrent data identify an association, do not tend to infer causality due to the nature of the design (Tabachnick & Fidell, 2007), and fail to address a more complex, bidirectional relationship between child behavior and parenting stress. Notably, longitudinal studies have been employed to investigate this bidirectional relationship.

Stress during Diagnosis: The participants experienced shock, denial, grief, and sadness upon hearing the diagnosis of their child with autism. Heiman (2002) claimed for parents, this is the most difficult and shocking experience to find out that there is a problem with their child. Tsao, Davenport, and Schmiede (2012) further state that the two opposing experiences of a family, which are the joyous experience of having a newborn baby and the painful experience of learning within few years that the child is disabled creates a high level of stress on the parents.

Stress during day-to-day lives: According to the finding of this study, within the caregiving responsibilities, managing the behaviors of their children with autism daily is challenging. Chee et al. (2008) claimed that parents' stress was situational and related directly to their role as a parent and their interactions with the child.

Lo (1994) investigated the care-taking responsibilities of parents and categorized their family life in four groups based on the age of the individuals with autism: infancy to early childhood, early childhood to late childhood, adolescence, and adulthood. This study indicated that the care-taking role of parents is present throughout the life of the child with autism where it is higher in the first stage; gets lower in the second stage, and increases in the third and fourth

stages. Although the current research did not compare the magnitude of the challenge of the caregiving role at different developmental stages as the above research did, findings concur with the presence of stress in caring for the children with autism. Therefore, the findings of this research and the above literature show that even after parents accepted the fact that their child has autism, the continuous care they must provide their children, mainly managing the children's behaviors and responding to their needs, is stressful for parents.

Managing the behavior of the child with autism, which is the major care-taking role of the participants, was found to be stressful for the participants of this study. Dzuby (2011) supports this finding by saying that a child's behavior related to having autism causes the greatest amount of anxiety and distress for parents. This is also substantiated by the study by Altieri (2006) who found that the combination of difficult emotional and physical behavior displayed by the child with autism creates a high level of stress for the entire family. Ritche (2008) further argues that it is no surprise that the caregiver of a child with autism may become distressed and begins grieving due to the lack of the child's ability to securely attach to them. Therefore, the finding of the current and above studies showed that parents are prone to stress because of the behavior of their children with autism.

The "bizarre responses" by children with autism's to various aspects of the environment, their pervasive lack of responsiveness to other people, resistance to change, peculiar interests, attachment to odd objects, resistance to a minor change in the environment, repetitive, peculiar hand/motor movements, unstable mood, unexplainable crying, laughing without unidentifiable cause, under/over responsiveness to sensory stimuli such as light, pain and sound, and when children behave in these unusual ways, dealing with even one of these behaviors is difficult and

magnified by combination of many of these behaviors (Altiere, 2006; Dzubay, 2011; Knudson & Coyle, 2002; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

The daily caregiving process associated with managing the behavioral problems and the nature of ASD is also psychologically damaging for caregivers. Schaaf et al. (2011) indicated that parents have to rearrange their daily routines to accommodate their child with autism as the child is unpredictable and often unable to regulate their behavior. Parents reported that routines were much easier to follow in familiar spaces such as their own home; however, more difficult in unfamiliar places such as another relative's home or public places in the community. The author claimed the parents' morning routines were the most difficult as meltdowns generally occur during this time due to sensory issues, causing the child to be late for school and the parent to be late for work. The current study's findings are similar to Schaff et al. (2011) in which participants reported changing their daily routines to support and accommodate their child with autism. Schaff et al. (2011) further reported, some participants were forced to leave full-time jobs to support their sons and two participants reported having to get their child ready before getting themselves ready each day, which often affected their professional life.

Stress about the future: The findings of the current study indicate that parents experience stress about the future of their children and their own future as well. Most of the time parents are the primary caregivers of a child. They are the ones who provide their child with autism with exceptional care no matter how distressful and frustrating the process is. They are the ones who can tolerate their children for lifelong treatment. So, the thoughts and worries about who is going to care for their child in their absence constantly bother parents. Heiman (2002) examined what aspects of the future worries parents and found that financial and physical independence, education, and how the children would manage themselves were primary concerns. Thus, parents

felt overwhelmed due to the inability of the child to be independent, the vulnerability of the child, the inability of the child to properly deal with psychosexual issues during adolescence, and the possibility of regression of the problem.

These findings in the current study are consistent with other studies (e.g., Bayat, 2007; Gray, 2002; Jardine, 2008; Mann, 2013; Murphy & Tierney, 2007), whereby the parents of children with autism felt great psychological distress due to worry about the child's level of independence and being a burden later in life, their inability to maintain relationships as well as worry about what would happen to their child if they became ill and could no longer take care of them. These findings are also similar to research findings of parents around the world including participants from the U.S. (Bayat, 2007; Myers et al., 2009), Australia (Farrugia, 2009), China (McCabe, 2008), Taiwan (Shyu et al., 2010), Iran (Samadi & McConkey, 2011), Turkey (Bilgin & Kucuk, 2010), Ghana (Anthony, 2009), Kenya (Gona et al., 2016), Israel (Shaked & Bilu, 2006), and South Korea (Kim, 2012).

Generally, the parents were not only concerned about the future of their autistic children, but also had even more concerns about their own future. "The looming thought is these parents will never be independent of their autistic child" (Koegel et al., 1992, cited in Glass, 2001, p. 124). This is a very powerful statement used by the author that affects most if not all parents of children with autism. Upon determining the leading source of anxiety and stress for parents of ASD, Koegel et al. (1992) affirmed the long-term burden of parenting an autistic child. The issue of separation becomes particularly critical (Lo, 1994). This could be at least in part since their child would be a burden to them later in life or due to lack of established residential settings to provide support for individuals (adults) on the spectrum (Parish-Morris, 2019).

6.4.2. Discussion on the Social Challenges

As forwarded in chapter four, participants' social life and participation in social events was very limited. In attending public places, the participants shared that a low level of awareness about autism was the main factor for experiencing social isolation, stigma, and embarrassment. This finding is consistent with Gray's (1994) study indicating that society had difficulty in accepting a child with autism. The low level of acceptance by society exposes parents to social stigma and embarrassment associated with inappropriate behavior displayed by the children (as cited in Altieri, 2006, p.15).

The major findings of the current study are discussed based on interpersonal loss (isolation) and restricted social life as well as negative reactions of the community and stigma. Their interpersonal relationships were negatively affected through reduced contact, isolation, or loss of relationships. This loss was attributed to the consequences of having a child with ASD (difficulties to manage the behavior of the child) and/or due to a hectic, busy daily schedule. Stigma was also noted as a draining factor for the participants' interpersonal loss. Hence, preference to isolate oneself and fear of taking the child in public were common social challenges. In line with this, DeMyer (1979) indicated that families fear their children's behavior and actions. Thus, parents prefer to isolate themselves instead of facing the frustration of taking their child out in public (cited in Altieri, 2006, p.15).

Discussion on Interpersonal Loss, Isolation, and Restricted Social life: The social life of the parents was found to be interrupted by the presence of a child with autism. Most of the participants reported a feeling of isolation as a result of a lack of public awareness surrounding ASD and/or because their child's challenging behaviors were likely to draw unwanted attention. This finding is similar to Heiman's (2002) who found that the presence of a disabled child affects

the parents' social life whereby parents rarely spend time with friends and lose contact with friends, relatives, or even with some of their extended family members.

Ludlow, Skelly, and Rohleder (2011) found that parents raising a child with autism are vulnerable to the judgment of others. Their results revealed these parents suffer from judgments due to the misunderstanding of others about the behavior of their child with autism. This misunderstanding involves others labeling children with autism as being badly behaved and viewing parents as lacking the ability to discipline their children. Meirsschaut, Roeyers, and Warreyn (2010) also highlighted the experiences of mothers raising a child with autism. In their study, participants mentioned that they are surrounded by individuals with little understanding of autism. They shared that they are easily criticized by others, which in turn led them to avoid social gatherings. Moreover, Bashir, Kurshid, and Qadri (2014) conducted a study in India that discussed parents' social isolation in the process of raising a child with autism. Their findings underlined various changes in their lives after giving birth to a child with autism. Among these changes, social isolation was experienced by a majority of the participants. Having their child as the center of attention and criticism left parents isolated and greatly affected their mental and physical wellbeing. Woodgate et al. (2008) constructed isolation of the parents by the theme, *'living in a world of our own,'* indicating the lack of understanding by society as a main contributing factor.

Our study also revealed the existence of social isolation from the community. The majority of participants confirmed that the unusual behavior that their child displays is not well understood within their neighborhood and society. Therefore, parents are forced to attend events without their children. However, attending social events without their children is also impossible for most of the participants, as they do not have anyone to take care of their child at home.

Hence, they are required to remain at home instead of attending social events. Neff and Faso (2014) indicated that parents raising a child with autism suffer from various challenging situations such as judgment and disapproval from others. Desai, Divan, Wertz, and Patel (2012) had similar findings of parents raising a child with autism in India and their refusal to send their child out in the community to play, celebrate events, or visit places. Such actions by parents, according to Desai et al. (2012) could result from parents' negative past experiences or expected fears of being isolated from the communities.

Embarrassment in social settings was also a challenge for some of the participants. The behaviors of their child with autism contributed to the parents being socially isolated to varying degrees. Participants in this study repeatedly stated that their child's situation affected their social life by isolating them from society. The parents attributed their embarrassment to the child's bizarre behaviors, rejection of their child by their peers, and/or terrible reactions or gestures from community members. This study is supported by Gray (1993) and Sanders and Morgan (1997) concerning embarrassment caused by the behaviors of children with autism. According to the author's report, the reason for the extreme embarrassment was because most autistic children have no physical abnormalities, which caused others to assume and perceive the child's behavior as a reflection of the parents' inability to properly socialize the children. According to Bevan-Brown (2004), Farrugia (2009) and Mak and Kwok (2010), embarrassment stemming from the difficulty of socializing was acutely felt by parents, and parents of children with ASD were treated as or perceived to be, bad parents.

Discussion on the Reactions of the Community and Stigma: The participants discussed how society views their children's developmental disorders which contributed to the occurrence of another subtheme—reactions of the community. The way the community reacts towards

children with developmental disorders had a significant impact on the participants. Reactions of pity, feeling sorry, and sucking one's lips had the effect of creating sadness and discomfort for the parents. This reaction might be because of a lack of awareness interacting with different cultural and religious explanations (Malik, 2011) and high misconceptions and assumptions about developmental disorders (Bashir et al., 2014a), which created the stigma in the community (Tilahun et al., 2016).

The findings within this subtheme were two types. Some reported sympathy and love from neighbors and community members towards their children similar to Murphy and Tierney (2007) who found that sympathy was extended to the parents of children with autism by different members of society. However, other parents explained how a lack of understanding by the public was difficult (gave them a hard time) and that being negatively evaluated by people around made them feel judged and stigmatized over time.

The current finding clarified that participants complained about the lack of understanding of autism by the society and the unsympathetic comments by the general public made them feel negatively evaluated, judged and isolated by people around them was consistent with previous studies (Aadil et al., 2014; Hoogsteen & Woodgate, 2013; Mann, 2013; Meirsschaut et al., 2010; Kuhaneck et al., 2010; Nyoni & Serpell, 2012). Moreover, others (Bakare et al., 2009; Bello-Mojeed, Bakare & Munir, 2013) not only found a very low level of knowledge and awareness about ASD among the general population, but a low level of understanding among even health care workers leading to the negative attitudes, avoidance, rejection, as well as negative comments. This stigma and discrimination according to the authors are manifested in rejection and embarrassment which is expressed through rumors, taunting, side talk, and nonverbal cues. This is consistent with the WHO (2003) publication on Mental Health that argued, stigma and

discrimination are manifested by “stereotype, fear, embarrassment, anger and rejection, avoidance and denial of the most common basic human rights” (p. 13).

Consistent with Getnet (2013), 77.7% of parents reported perceived stigma and about 44.4% of the parents in this study perceived stigma ‘often or a lot’ because of their child’s situation (Tilahun et al., 2016). Most of the participants in the qualitative study spoke of stigma in a way that is consistent with the findings of Gray (2002) in Australia, and Mak and Kwok (2010) in China. The most common examples of stigma by association reported by parents in this study included being avoided, glared at, blamed, disregarded, and given unsolicited advice. Farrugia’s (2009) study also revealed unfriendly looks and staring.

Associating the developmental disorder with supernatural power and lack of understanding of ASD are mentioned as factors that make parents vulnerable to social stigma. Lack of knowledge and a widespread belief that associates mental illness or developmental disorders with supernatural power make millions of families struggle with its social consequences (Alem et al., 1999; Shibrei et al., 2003; 2008). Considering the child to be lazy, and foolish; viewing the behavior as deliberate and rude; and negative labeling such as dependent and helpless, thoughtless, dangerous, and unpredictable are among the reasons that parents face stigma (Seltzer et al., 1995; Shibrei et al., 2003). Similarly, a study by Getnet (2013) found that attitudes towards people with a developmental disability and their families in Ethiopia are still characterized by stereotypes and prejudice, based on traditionally held views that link disability with punishment and curses.

The experience of stigma and the feelings it provoked in participants could be related to the proximal processes in Bronfenbrenner’s (1986) ecological system theory. Participants were concerned about stigma and other people’s perceptions of ASD. Stigma could influence the

relationships that some participants had with family members, occurring at the level of the microsystem and the mesosystem (in their relationships with professionals and significant others). Lilley (2012) also identified the presence of stigma at a macro-systemic (communal) level, which was manifested in the form of lack of understanding and negative comments which make the participants feel judged (if it is rooted in a culture's overarching beliefs and values).

6.4.3. Discussion on Financial Challenges

Caregiving for autistic children is expensive for parents. According to Saunders et al. (2015), families of children with ASD had a significant level of financial hardship because of their children's special needs care. A large proportion (nearly 90%) of our quantitative respondents had financial difficulties. Jarbrink et al. (2003) asserted that the financial cost of raising a child with a disability is estimated to be approximately three times greater than the cost incurred in raising a typically developing child. Participants in the qualitative part of our study attributed the financial burdens to clothing, food, medication, additional care, and treatment such as speech, cognitive, social skills therapy, and transportation costs. The parents explained that to keep the personal hygiene of a child with autism, extra clothing and sanitary pads are needed daily. In the provision of a balanced diet, the high cost of food items is also challenging for the parents. Sharpe and Baker (2007, p. 248) endorsed that many intervention strategies require long hours of one-to-one interaction with a trained therapist, and the use of costly foods or drug supplements. Parents of a child with autism often face greater outlays of time and money than they would for a typically developing child. However, the finding from the authors did not indicate a specific figure for the cost of intervention strategies and interaction with trained therapists.

According to some qualitative method participants, children with autism have special needs that require enormous investment. Similar to other children, parents need money to satisfy the needs of their children, including a balanced diet, clothes, and other basic needs. Those with relatively better economic status can at least provide the material needs of the children. However, parents with no sufficient source of income are likely to be challenged to meet the needs of their children. For instance, findings from Weiss, Wingsiong, and Lunskey (2013) revealed that parents raising a child with autism face different demands that require adequate income. As parents fail to meet these demands, it can lead to a crisis. A study by Dababnah and Parish (2013) in the West Bank stated that parents raising a child with autism experienced financial hardships to meet their children's needs. Myers et al. (2009) noted that parents mentioned struggles concerning different expenses while raising their autistic children such as costs for therapies, special schools, and special diets. According to Ganz (2006), the lifetime costs of autism including direct and indirect costs have been estimated at \$1.4 million for someone without an intellectual disability and \$2.3 million for someone with an intellectual disability.

The long-term cost of medical treatment and custodial care is also a challenge for parents (Seltzer et al., 1995; Shibrei et al., 2003; 2008; WHO, 2003). Besides the medical cost and custodial care, costs for livelihood and other basic needs are waiting to be covered by the parents. Furthermore, the impact of autism on parents' labor market participation was noted by Gould (2004) who stated "one or both parents often must reduce work hours or step out of the labor market altogether" (as cited in Sharpe & Baker, 2007, p. 248). Financial stresses of parents are also linked to costs of unfunded therapies, unexpected costs, and the necessity of having flexible work schedule/loss of potential earning (Bevan-Brown, 2004; Hastings & Johnson, 2001; Gupta & Singhal, 2005).

Generally, these financial, psychosocial, and caregiving burdens led parents to feel embarrassed about their child's condition. In their responses, participants highlighted the psychological, social, and financial burdens associated with raising a child with ASD in Addis Ababa, Ethiopia. This finding is similar to the results of Karst and Van Hecke (2012) that revealed ASD has impacts on parents that included financial burden and poor quality of life; and Lai et al. (2015) also asserted that individuals with ASD and their parents are facing emotional, social, and financial burdens due to the lack of knowledge about the disorder, and inaccessibility of better supports and services among the public.

6.5. Discussion on the Coping Mechanisms

The present study has sought to identify the coping mechanisms and most used coping strategies employed by parents of children with autism. Despite the adverse situations, financial constraints, and limited services, the majority of parents had innovated strategies for creating a secure, loving, and rewarding space for their children and families. Parents used different coping mechanisms while they struggle to manage their caregiving burden. As Lazarus and Folkman (1984) argued, individuals' adjustment to the stressful situation depends on the strategies adopted by the individual and the resources available to facilitate coping.

Parental Stress and Coping Mechanisms: In this study, a significant negative relationship was found between each subscale of the F-COPES and total parental stress, as measured by the PSI-SF. The results demonstrated that parents with lower degrees of stress tended to have higher degrees of resilience in each subscale, and parents with higher degrees of stress tended to have lower degrees of resilience in each subscale. Coping strategies were found to predict parental stresses. There is an inverse relationship with increases in coping behavior associated with decreases in parental stress level (Lai et al., 2015).

Commonly, two ways of coping are described: positive and negative strategies. A study by Tway et al. (2007) reported that the use of positive approaches are associated with better adjustment, whereas the use of negative (avoidance) strategies are associated with poorer outcomes. Thus, it is claimed that parents with positive coping skills present decreased levels of stress (Erguner-Tekinalp & Akkok, 2004). These strategies included coping through religion, acceptance, reframing, advocacy, patience, and perseverance, and seeking social support (Gray, 1994; Woodgate et al., 2008).

Discussion on Coping through Religion: Parents used different resources to cope with the difficulties of having a child with a developmental disorder. The religious-based coping strategy that was identified in this study was similar to one study in Kenya by Gona et al. (2016) who found that parents used religious coping which was manifested in acceptance of the child's condition through prayers and active searching for spiritual healing. The most widely used coping strategy reported by participants of this study was seeking spiritual support (religious-based coping). Some of the parents stated that they relied on spiritual values and used spiritual healing methods such as holy water and prayer. With these efforts they hoped to decrease the developmental problems of their children and the stresses that emanate from caring for and managing their children's behavior. Others coped through religion as a result of finding people who understood them while involved (engaged) in Bible studies and church programs.

Seeking spiritual support has been shown to correlate with parental distress. The parents were able to find solace in religion because it can give them strength to continue with their lives despite the challenges of the extra burden of taking care of the child. Several parents additionally reported religious beliefs as a coping strategy and helping them to accept and raise a child with ASD (Chong & Kua, 2016; Ilias et al., 2016; Santoso, Ito, Ohshima, Hidaka, & Bontje, 2015).

For example, parents accepted their child as a gift from God, despite his or her ASD diagnosis, found comfort through prayer (Santoso et al., 2015), and/or by reading holy books and/or through church involvement (Ilias et al., 2016). The results of the current study suggest a correlation of religious coping with lower levels of parental stress. Bristol (1984) also found that belief in God and/or adherence to clear moral standards mediates the family hardships by giving meaning and purpose to the sacrifices they make in caring for the autistic child.

The finding is also consistent with Gray (2006) who indicated religion was a coping strategy that remained the same over time in his studies (Gray, 1994; 2003; 2006). For Gray, the parents may have found it more important to acknowledge the permanence of their child's disability and find a way of thinking about it that puts it into a meaningful perspective through religion. Accordingly, Nyoni and Serpell (2012) claimed that when parents found themselves in a state of helplessness, they engaged in spiritual beliefs as faith in God plays an important role in the reduction of stress for parents with disabled children.

Other researchers (e.g., Baba, 2014; Bayat, 2007; Dardas, 2014; Durban et al., 2012; Wiggs, 2010) testified that parents were able to find solace in religion. Being involved in a Bible study can give them strength to continue despite the challenges they face (extra burden of taking care of the child on the spectrum).

Belief System: For some qualitative participants, their belief system greatly helped them throughout their journey. They mentioned different types of religious activities that gave strength. Their belief is a source of hope and positive expectations. In highlighting the role of the belief system as a resource, Myers et al. (2009) reported that parents found their spiritual life was enriched due to the situation of their child. Parents in their study stated that they can see their child as a unique gift provided to them and they viewed autism as a calling to get closer to their

creator or divine power. The study by Greeff and Vander-Walt (2010) also highlighted parents who viewed their faith in God as the main factor facilitating their adaptation process. Their faith has allowed parents to have purpose and meaning in their lives. Faith in God was rated by the families in their study as an important factor contributing to adaptation. Likewise, Dababnah and Parish (2013) mentioned that parents' belief system helped them to accept their situation. Some of the participants in their study described their condition as a God-given situation in which they have no control.

Traditional treatment such as prayer, holy water, traditional medicine, witchcraft, and rituals were also found to be a coping strategy (Alem et al., 1999; Shibrei et al., 2008). As indicated in these studies, there are conditions in which culture becomes an obstacle but on the other side, people may also use it as a coping strategy. This is consistent with ecological systems theory that states culture played a pivotal role in the perception of challenges and coping mechanisms used by parents (Lamanna & Riedmann, 2000).

Discussions on Coping through Acceptance of the Situation: Acceptance plays a key role in allowing parents to take action and seek treatment for their child affected by autism. In our study, the role of acceptance in moving towards action has been repetitively highlighted by parents and the key informants. Accepting the situation of the child is approaching halfway closer to the solution. Some of the parents (qualitative participants) who accepted the situation seem fully committed to providing better care and support for their children.

The findings of this study also demonstrate that acceptance is a process that requires a certain amount of time until parents internalize the life-altering situation of their child (Balfour, 2007). Although time is a necessary element in the process and depends on the personality of an individual (Jardine, 2008), both organizations are highly engaged in supporting parents using

various training and counseling sessions. Fortunately, both organizations are owned by women who also happen to have a child affected by autism. This provides a ground for parents to easily communicate their issues with the owners. It also makes it easier for the owners to share their experiences with parents about the journey of raising their own children. Parents who accepted the situation of their child easily move on to seeking ways to provide help, as the key informants claimed.

Regarding the process and role of acceptance in strengthening the parents of a child with ASD, Hoogsteen and Woodgate (2013) reported that parents raising a child with autism pass through a phase of emotional breakdown before attaining a certain level of acceptance. Their findings confirmed that after a certain period of sadness, parents were able to accept the situation and then proceed towards the solution. Lutz, Patterson, and Klein (2012) also confirmed that mothers raising a child with autism passed through several stages until they reach the level of acceptance. They mentioned that adaptation takes place through a journey of grief and anger. However, once mothers reach the level of acceptance, they tend to work for a better future for their children. Altieri and Von Kluge (2009) highlighted that despite the emotional hardships and personal struggles, after acceptance, parents are able to pull on their resources for the improvement of their child.

Jardine's (2008) participants also described a process of accepting and adapting to their child's autism to provide the best life they can for their child. Acceptance is an important experience that facilitated their ability to cope with their child's autism. Furthermore, Hoogsteen and Woodgate (2013) and Mierau (2008) indicated parents used acceptance as a means of positive personal development and empowerment that directed them to concentrate on learning new skills such as research and advocacy.

Discussion on Coping through Reframing: Adversity has the potential to disrupt personal and family integrity and create a crisis of meaning for those involved (Walsh, 1996). Reframing or meaning-making continues throughout the coping process, from the initial appraisal to subsequent reappraisals (Lazarus & Folkman, 1984). The findings showed how parents reframed their child's diagnosis and what it meant to be a parent of a child with ASD. Taylor (1983) proposed that people adapt to threatening events by making meaning of the experience, working to regain mastery, and bolstering self-esteem. An effort to make meaning of stressful circumstances and gain coherence contributes to building competence and confidence during the coping processes (Walsh, 1996). Positive reappraisal can also facilitate purposeful planning (Folkman et al., 1986) and lead to personal transformation over time (Lutz et al., 2012; Marshall & Long, 2010).

According to Pearlin and Schooler (1978), how we perceive or interpret the situation can neutralize its negative characteristics. A positive appraisal and reconceptualization of what is 'normal' can be a powerful tool that families use to minimize the effects of stress in their daily lives (Gill & Harris, 1991). In this study, reframing or a positive reinterpretation helped parents to restore the disequilibrium created by the diagnosis and outsiders' judgment of their child's behavior. A positive reinterpretation of stressors allows parents to exert control over their situation in an attempt to master it (Carver, Scheier, & Weintraub, 1989).

The meanings parents give to the experience of raising a child with challenges illuminate societal interpretations of difference and efforts to reconcile these differences. Parent perspectives revealed their efforts to cope with the challenges associated with parenting a child with a 'disorder'. A few of the parents rejected a medical interpretation of their child and 'disability as tragedy' (Oliver, 1986), and most commented on their child's great potential. Their

outlook embraced the constructive aspects of their child's strengths and attributes and challenged the deficit view. In a doctoral study, Inglis (2006) found that parents described their child's strengths as being loving and affectionate, and funny and engaging. Woolfson (2004) also asserted that when a parent reappraises their view of disability to one that promotes a positive identity, their self-efficacy improves. Thus, for the parents, their child was first and foremost their child, and being different was not viewed as wrong or lesser than.

Parents reframed their perspective to one of the possibilities and what 'normal' was for their child and their families. For example, parents valued their child's differences and adjusted their approach to alleviate pressure from trying to conform to societal standards that were at odds with their child. This finding agrees with Levine's (2009) study of single mothers and how they transformed their positions from their child being 'disabled' to 'different' or 'normal'. Families formed a new concept of normality as they adjusted the fit between their environments (Walsh, 2003) and tempered the dissonance between other people's perceptions of normal and their child's differences (Huws, Jones, & Ingledew, 2001). Likewise, according to Pritzlaff (2001), reframing was one of the effective coping mechanisms parents use. They capitalized on their own and their child's strengths. Most of the qualitative respondents in our study have accepted their children for who they are and advocate for what they can be.

Discussions on Coping through Advocacy: The appropriate resources help parents manage the demands in their environments, strengthening their sense of coherence and promoting health (Antonovsky & Sourani, 1988). In this study, some parents spent considerable amounts of time searching for information; pursued advice and intervention from specialists in the health systems, and connected with other parents of children with ASD for practical and emotional support. Parents seek advice, assistance, and information, as well as moral support and

understanding (Carver et al., 1989; Mackintosh, Myers, & Goin-Kochel, 2005). The diagnosis presented a turning point for many parents and prompted a concerted effort to find relevant information and resources. Searching for information after the diagnosis can help manage the overwhelming emotional impact of receiving a diagnosis (Lutz et al., 2012) and help parents regain some sense of control over a new and challenging situation (Marshall & Long, 2010).

The majority of parents reported that in addition to autism centers, other parents of a child with autism were a great source of information and knowledge to educate themselves on many aspects of autism. For others, the knowledge they acquire through the internet and books helped a lot when it comes to managing their children's behaviors and teaching them important skills. Comparable with the current study, Murphy and Tierney (2007) proposed that to cope with the associated challenges of having a child with autism, parents valued the information from a variety of sources including the internet and other parents of children with ASD. Likewise, Kuhaneck et al. (2010) recognized participants' own knowledge as the key to successful advocacy for their children.

When parents encountered gaps in services, they sometimes moved into activism and advocacy roles which can result in a sense of empowerment. Parents expressed a strong desire to help others, and through their fight to secure services, they wished to prevent other parents from experiencing the same frustration and feelings of isolation that they had experienced. This sentiment is similar to Ryan and Cole's (2009) qualitative study of mothers of children with ASD. They felt their struggles for finding a diagnosis; securing support for their child's needs at school and searching for family counseling could be informative for other parents and teachers. They too had developed skills through their search, conferring with specialists and navigating through the health and education systems for services and supports.

Discussions on Coping through Patience and Perseverance: Positive emotions such as patience, a sense of humor, having a positive outlook, and optimism help individuals to cope effectively with stress by regulating negative responses and opening up thinking for possible solutions (Tugade & Fredrickson, 2004). Walsh (2006) states:

A positive outlook is found to be vitally important for resilience. Key elements involve hope and optimism; focus on strengths and potential; initiative and perseverance; courage and en-courage-ment; and active mastery and acceptance. All are essential in forging the strength needed to withstand and rebound from adversity. (p. 64)

The parents in Altieri and Von Kluge's (2009) study spoke of 'enhanced' patience and perseverance. Brett captured it aptly: *"You've just got to have a lot of patience and you've got to persist at it..."* He tried *"not to sweat the small stuff"* and said that he was confident that being patient with his son was *"going to pay off in the end."* Durand (2014) ascertains that parents' optimistic approach to themselves and their child influences their success in helping their child behave better. There were several parallels to the findings from King, Baxter, Rosenbaum, Zwaigenbaum, and Bates's (2009) study of 16 families of children with ASD and Down syndrome as parents demonstrated optimistic perspectives by focusing on their child's potential and strengths, accepting difference, and striving to change the environment. Parents' continued willingness to ask for help reflected their great need as well as their perseverance. The growth in patience and persistence or persevering towards a goal despite barriers (King et al., 2009) has been noted in studies of Altieri and Von Kluge (2009) and Bayat (2007) who found it was necessary to successfully manage their child and the wider challenges associated with the ASD.

Discussions on Coping through Seeking Social Support: Social support was found to be a coping mechanism that was frequently reported in easing parenting stress (Chong & Kua,

2016; Santoso et al., 2015). Specifically, social support was attained through numerous sources, which included support from the immediate family, schools, families of other children with ASD, professionals, and/or extended family members (Chong & Kua, 2016; Santoso et al., 2015). The participants of this study described other parents as a source of information and also discussed the kinds of social support they received from spouses, extended families, and organizations. Some of the parents reported the support of the center was important because their children's stay there gave them relief from the busy days they had in managing them, and allows them to easily meet and discuss with other parents of a child on the spectrum.

Similarly, Mann (2013) indicated that the Jamaica Autism Support Association (JASA) was a significant source of support in creating the opportunity to connect with other parents raising a child on the spectrum through a support group or parent connection network at the center. Gray (2006) also demonstrated that participants reported the child's attendance at a center provided daily respite and the opportunity to make use of the counseling services provided by the staff (social workers). Bayat (2007) further indicated the most useful source of formal support for the participant seems to be parent support groups, where they feel free to discuss their concerns about a child with autism without fear of being inspected.

Spousal support and support from extended families were other types of social support found to be helpful in the current study similar to the studies by Kuhaneck et al. (2010) that indicated participation of their spouses in the parenting and care coordination activities of raising a child with autism as critical. Furthermore, Baba (2014) reported that help from extended family members was another important resource. According to Dardas (2014), the extended family system in the traditional Arab cultures was found to be significantly helpful for individuals caring for children with autism, especially to reduce daily stressors. According to Ludlow et al.

(2011), parents who were able to get support from extended families were able to better cope with their situation and have a positive experience.

6.6. Discussion on the Available Supports for Parents of a Child with Autism

Dunn et al. (2001), Pottie and Ingram (2008) and Sivberg (2002) stated that having a child with an ASD can be a difficult experience for parents and thus it is important to identify available supports for parents raising a child with an ASD. Since supports are associated with positive adjustment in the individual caregiver (as cited in Karst & Van Hecke, 2012). Social support can provide practical assistance and resources for this population at risk. In a qualitative study of mothers of high school students with ASD, Plant (2011) explored maternal experiences with social support, both formal and informal. Mothers shared that as a result of the support, they were able to resolve problems better and function on a higher level. These studies illustrate the significance of support in parents' lives to counter the demands associated with challenging circumstances.

Parenting Stress and Social Support: One of the factors that significantly attenuates stress in parents of a child with ASD is social support (Bitsika & Sharpley, 2004). In our study, higher levels of social support (as measured by the FSS) were correlated with lower levels of parental stress (as measured by the PSI-SF). Sharpley and Bitsika (1997) reported that social support acts as a buffer against stress for parents of children with ASD. Ello and Donovan (2005) reported similar findings, asserting that social support serves to mediate parental stress. Like the work of Gray and Holden (1992), who found social support to be a powerful predictor of maternal depression, anxiety, and anger, our study indicates that higher levels of social support were associated with lower levels of parental stress.

We have defined coping as strategies and actions that are marshaled to manage a challenging situation; and support as the availability of instrumental or emotional support from formal (e.g., agencies) or informal networks (e.g., friends and relatives) (Freedman & Boyer, 2000; Nabawy & Moawad, 2012). Studies (Benson, 2006; Boyd, 2002) have indicated that both formal and informal support play an equal role in lowering self-reported rates of parenting stress, while others (Ekas, Lickenbrock, & Whitman, 2010; Gray & Holden, 1992; Hastings & Beck, 2004) have indicated that formal support (such as support coming from professional organizations) is the more significant type of social support to buffer against heightened levels of parental stress. The present study indicated both formal and informal supports were negatively correlated with parenting stress. This result is consistent with studies by Benson (2006) and Boyd (2002) indicating that both forms of supports may serve as a buffer against heightened levels of parental stress.

All the parents in qualitative study indicated the importance of having a great support system. Their support systems consisted of informal (spouse, relatives, friends, and other parents of a child with autism, neighbors, and religious leaders) and formal (hospitals, Joy, and Nehemiah Autism Centers, and professional agencies) forms of support. Social support theory focuses on family well-being and the importance of a support network to the overall health of individual members of a family unit (Armstrong, Birnie-Lefcovitch, & Ungar, 2008), whether it is informal or formal.

6.6.1. Discussion on Informal Supports

Ekas et al. (2010) argue, “*Social supports could be conceptualized as providers of knowledge as well as instrumental and emotional support. Social support empowers parents by giving them hope and leading them to positively appraise the future*” (p. 1282). Receiving support helps to alleviate stress for the parents (Guralnick, Hammond, Neville, & Connor, 2008). Unluer (2009) reported that once there is a support, primary caregivers experienced a decline in their stress levels. According to Kaner (2009), other family members, neighbors, peers, and the wider community may serve as sources of social support that were necessary for parents and/or primary caregivers.

Spousal Support: The sharing of parental duties, spousal communication about their feelings concerning their autistic child, mutual respect, and the acknowledgment of each other’s daily accomplishments allow a pathway for proper family development. In this study, the qualitative data demonstrated that, though all-of-the male and the majority of female participants claimed their spouses were supportive, only a few mothers were receiving little or no support from their husbands.

This study differs, concerning spousal support, from studies by Milgram and Atzil (1988); Konstantareas and Homatidis (1989); and Konstantareas, Homatidis, and Plowright (1992). They reported that parenting burdens were not shared equally between the mothers and fathers of an autistic child, with mothers assuming most of the responsibility. They also reported feelings of resentment by the mother and portrayed mothers as always insisting the fathers have to do more.

Support from Relatives, Friends, and Neighbors: while relatives, friends, and neighbors can be an important source of support, a few parents felt rejected. In a study of three families of children with autism Schall (2000) found that all three families shared stories of rejection by family, friends, neighbors, and strangers in the community. Similarly, in the current study, almost half of the parents who participated in the qualitative interviews felt they were not accepted or understood by their relatives, friends, and neighbors.

Some of the participants said that their family members are sympathetic towards the child and themselves and were actively involved in providing care and support as well. The attitudes of extended family members, friends, and neighbors varied from one family to the other. As mentioned by Fairthorne, Fisher, Bourke, and Leonard (2014), almost half of the mothers benefitted from helpful and supportive family members in a study conducted in Australia. In Kentucky, Wolf (2009) found that 61.5% of parents had other family members help with child care. Increased coping skills were also evident in parents having sufficient support from family members, friends, and other parents of a child with autism.

Some participants said that their family members, friends, and neighbors are not sympathetic towards either the child or themselves. A very few of them mentioned their relatives treat the child differently and/or criticize and blame the parents. According to Dehnavi, Malekpour, Faramarz, and Talebi (2011), the main sign of autism is a behavioral problem; therefore, people might ignore their neurological problem and blame parents for their children's misbehaviors. Some parents reported that extended family members blame parents for their children's disorders (Tarabek, 2011). According to Altieri (2006), extended family members may sometimes reject the child with autism or distance themselves from the parents of a child with autism. The parents often described relatives as cold, distant, and generally unhelpful. The

author further stated that low family support may decrease parental quality of life and increase the burdens for parents in coping with a critical situation.

Support from the Community: As confirmed by the qualitative findings of the study, few respondents believed that most of the members of the local communities exhibited positive responses towards their children irrespective of their impairment. These parent respondents explained that the positive response of the local community was manifested through sympathy and love for their children. However, the majority of the respondents argued that the reaction of local communities towards children with autism was negative and disappointing. The children with autism are isolated; mistreated by their peers without disabilities and other members of the local community. In the current study, some parents of children with ASD were experiencing significant levels of fatigue because of the judgments and negative attitude of the community while some coped by advocating and educating others about autism. Thinking the root cause is a low level of awareness in the community, the parents recommended a change in attitude towards the children and the disability stemming from the disorder.

Moreover, lack of societal and family support is also responsible for their increasing burden. It is mainly due to a lack of knowledge about this disorder within society; they usually show stigmatized attitudes towards children with autism and their parents. Parents with a low level of awareness about this disorder therefore sometimes feel guilt and self-blame for their child's condition. Overall, parents of a child with autism face different challenges with regard to psychological, financial, social, and familial aspects that need to be considered in support provisions.

6.6.2. Discussion on the Formal Supports

Unlike parents of typically developing children, parents of a child with autism must rely on specialized support systems to reduce the challenges and aid the coping responses of parents in caring for their child. Though special support is not provided by the government in Ethiopia, participants of this study benefited much from the centers' support systems such as the provision of life skills training, lunch, and transportation for their children, as well as counseling, monthly training, and parental support groups. The participants were provided with all the types of support the centers offer.

6.6.2.1. Discussion on Types of Supports: Due to the supports from the centers, the children's self-help skills (such as toileting, eating, shopping, dressing, and playing) and parents' awareness about autism were also enhanced. In line with this, Mancil, Conroy, and Nakao (2006) conducted a case study that examined a child's problem behaviors in the home and reported decreased problem behaviors as a result of parents' training. The finding also suggested that providing different supports and training for parents of children with ASD greatly increased the child's abilities.

Though counseling is provided based on the needs of parents, Joy and Nehemiah Autism Centers are delivering training once a month to positively influence a child's development. According to Dillenburg, Keenan, Gallagher, and McElhinney's (2002) study, parental education influences expectations, in that, having higher parental education is significantly related to having higher expectations of children's achievement. The authors also defined parental education as an effort that attempts to enhance or facilitate parental behaviors that would influence positive developmental outcomes in their children.

The primary focus of parent education programs, in general, is that of teaching discrete skills that are designed to aid parents in managing problem behavior, teaching skills to their children, and improving the quality of the parent-child relationships (Kaminski, Valle, Filene, & Boyle, 2008). Parent education differs from psycho-education, which is typically designed to teach parents particular knowledge-based content (e.g., what is autism?) as opposed to skill-based content (e.g., how to implement treatment for autism). According to the seminal work of Forehand and McMahon (1981), behaviorally-based parent education programs are well-established, empirically supported treatments for a variety of childhood problems.

Parent groups have the potential to meet the needs of their members powerfully and satisfyingly. Shared experiences strengthen the bonds within the group and supplement ties lost as a result of parenting a child with ASD. Participating parents can pool their knowledge, share strategies, and advocate for better services. There are opportunities to “co-construct a group narrative” that can serve as a collective identity (De Wolfe, 2013, p. 186) or there is potential for the members of the group to gain resilience collectively. Furthermore, a solid network can be achieved on the national level when collaboration between vested groups is encouraged (Luthar & Cicchetti, 2000). In contrast to studies by Sanders and Morgan (1997), Norton and Drew (1994), Dunlap and Fox (1999), and Sharpley and Bitsika (1997) which emphasize the need for support and respite care, in our study, it was revealed that no respite care support is provided and available for the parents of a child with autism in Addis Ababa, Ethiopia.

6.6.2.2. Discussion on Strength of the Services

Changes/improvements after joining the centers: The participants in the qualitative component reported that after their children began attending the centers, they observed progress in their children’s development of self-supporting skills such as toileting, eating independently

and making sounds, improved sleeping times, washing face and brushing teeth, putting on and off socks and shoes, behaving politely, and keeping their hands clean and sanitized at meals. Ozonoff and Cathcart (1998) reported significant progress in increased cognitive and developmental skills by children enrolled in an intervention program and parent-taught program at home. Furthermore, according to the above authors report, parental involvement resulted in increased skills and progress for the child.

Communication between Parents and Teachers: Joy and Nehemiah Autism Center teachers and parents have good communication, by using methods such as a communication book, phone, face-to-face and interestingly, regular monthly meetings to discuss and share experiences. A study carried out by Howlin and Yates (1990) showed that direct teacher-parent communications may not only improve the quality of interpersonal bonds between teachers and parents but also can permit the disclosure of child-specific information, which allows teachers to better understand their students' strengths and promote student success in and outside the classroom.

For strengthening the degree of communication between parents and teachers at special schools, Kaner (2009) have suggested that psychologists play an essential role and can assist teachers to enhance their communication skills with parents, as well as develop methods for organizing effective parent-teacher conferences. Psychologists can also encourage the involvement of parents' in-home and school-based interventions. In this view, Burrell and Borrego (2012) indicated that it was essential for parents to have an actual connection with the school because it permitted them to better comprehend their child and their child's school experience. Similarly, Wieder and Greenspan's (2003) study illustrated the effect that lack of parental involvement could have on a child with autism and showed a statistically significant

trend between uninvolved parents and children who did not make much progress. The authors highlighted and underscored the importance of parental involvement for the success of a child and program.

6.6.2.3. Discussion on the Limitations of the Services

Inadequacy of the Services: Most of the parents complained about long waiting times for the diagnoses and unanimously asserted that there was no special support for children with ASD and their parents provided by the government. Howlin and Asgharian (1999) found that parents of children with ASD experienced longer delays in obtaining a diagnosis, likely due to the more complex nature of the disorder. The authors further claimed parents are significantly less satisfied with the diagnostic process.

Kohler (1999) found that families generally used several services to benefit both the child and the family. In terms of difficulties experienced in obtaining services, more than a third reported being placed on a waiting list, and several others either found it hard to obtain services in school or were not able to obtain any services in the community. Kohler (1999) claimed that parents identified such difficulties in accessing services. Obtaining services is more than just a simple referral. Parents are often frustrated with a long waiting list and in some case no services at all. As Samadi, McConkey, and Kelly (2012) described, students with autism in low-income countries are not receiving sufficient special education support because of the lack of readiness of the school, the limited ability of teachers to meet the special education needs of children with ASD, and a shortage of qualified professionals in the area.

These findings were corroborated with the information from a study in Nigeria by Eseigbe et al. (2015) that revealed the high cost of special care for children with ASD and the

lack of professionals to provide specialized services as among the challenges in managing the disorder. Nwanze (2012) similarly reported that there is a scarcity of qualified staff and programs to assist families affected by ASD. Nonetheless, the UN Convention on the Rights of the Child Articles 2 of 1989 stipulates that member states allocate the necessary resources and other support so that children with disabilities can access education. Therefore, the results of this study help to further highlight the low support for ASD in Addis Ababa that requires attention to improve outcomes for children with ASD and their parents. Networking, advocating, and allocating budgets to meet the needs of these vulnerable groups are thus needed.

In summary, many parents and families do not have enough supports (FSPC, 2007). This is particularly true for parents of a child with autism. Because of ASD's unique characteristics, the care of children with autism is often very challenging and stressful for parents (Meadan et al., 2010). The parents' numerous roles and responsibilities in caring, guiding, supervising, and overall development of the child are further challenged by the absence of services for their children with autism. They were not able to find schools or hospitals that could accommodate them based on their autistic behaviors. Lewis (2009) noted the lack of autism services in Ethiopia. The impossibility of meeting the educational needs of all disabled children through segregated education is due to the fact that only two special schools for children with autism (neither of which is a government-run program) exist in Ethiopia.

Regarding the policies developed in Ethiopia concerning education provision for children with special needs, Lewis (2009) claimed that education policies and plans in Ethiopia have attempted to explain the direction their education sectors should take to ensure education for learners with special needs. However, clarity on how policymakers interpret the key concepts of special needs education and inclusive education remains elusive. Challenges of inadequate social

services experienced by parents in this study are similar to what was found in South Africa by Balfour (2007) where the absence of a health care system which includes specialized professionals is disappointing and challenging for parents.

Lo (1994) described social support as a part of a network of mutual communication and obligation. The majority of the participants reported getting emotional support and understanding from relatives, neighbors, friends, and significant others but on a limited basis. The support given to the parents of children with autism should not be limited to certain events; rather it should be delivered in a planned and systematic way. Therefore, since the presence of a child with autism makes the parenting role more difficult compared to parents of a typical child, provision of support is unquestionable and helpful for parents to cope better.

6.7. Discussion on the Positive Experiences of the Parents

This study explored the experiences of parents in raising a child with developmental disorders, specifically ASD. Parents were given the opportunity to describe their experience from the diagnosis, through challenges, coping mechanisms to supports. Even though mostly focused on the challenging aspects (Matenge, 2012; Tadesse, 2014), caring for a child with autism has a positive side (Nurullah, 2013) further illustrating the quote, *“parenting a child with autism is not all bad”* (Weastell, 2017, p. 56).

A challenging or stressful experience does not always result in negative outcomes; some people may experience it positively (Somerfield & McCrae, 2000). Bayat (2007) claimed some families of children with autism are believed to gain strength despite adversity. Results from the Bayat’s retrospective survey of 175 parents suggested that those who used internal processes such as attributing positive meaning to disability showed greater wellbeing. Similarly, Pottie and Ingram (2008) provided evidence that caregivers cannot only protect but improve their

wellbeing. Their 12-week daily diary study of 93 parents showed that those participants who used positive reframing of their experiences with their child noted an increase in daily positive mood. In perhaps the largest study noting positive parental experiences, Myers et al. (2009) asked 493 parents to answer the open-ended question: “how has your child in the spectrum affected your life and your family’s life?” Out of the 24 total resulting themes, 9 were deemed positive. Of these nine themes, positive emotions were noted as important benefits arising from the caregiving experience and included feelings such as compassion, tolerance, patience, and joy. These emotions included joy experienced through seeing their child grow, laugh, and develop, as well as love, hope, and optimism (Altiere & Von Kluge, 2009; Ekas et al., 2010; Kayfitz, Gragg & Orr, 2010).

In our study, the parents’ positive experiences as a byproduct of nurturing a child with ASD have resulted in positive emotions (love and gratitude), positive engagements (connection with others and opportunities), and positive spiritual developments. As indicated by Stace (2011) when she explored how to include the experiences of families of children with ASDs in New Zealand’s autism policy, the positive emotion of love was an important and prevailing experience of caregivers of children with ASD. Similarly, in this study, parents felt a strong sense of love for their children. The other positive emotion noted by participants was that of gratitude. Gratitude has been identified in studies of parents of children with ASDs by both Bayat (2007) and Myers et al. (2009).

Myers et al. (2009) reported that parents expressed an increased sense of appreciation (or gratitude) through their experience of caring for their child. For these authors, gratitude was directed towards an appreciation of the unique qualities of the child with an ASD, a finding reflected in the results of a study by Altieri and Von Kluge (2009). These experiences of

appreciation and positive emotion are theorized to be important for caregivers not only for their ability to elicit pleasure from the experience on that occasion but also the ability of positive emotions to encourage sustained wellbeing of the caregivers (Ekas et al., 2010; Kayfitz et al., 2010).

Besides the positive emotions, parents indicated several positive engagements as a byproduct of raising their children. Interestingly, whilst some participants spoke of a loss of connection with their spouses, others noted greater connections. Participants also noted improvements in the quality of family and friend relationships, as well as the establishment of new connections with other parents of a child with ASD. This verifies findings of Bevan-Brown (2004) whose participants noted both losses and gains in interpersonal relationships, and Kayfitz et al.'s (2010) discovery that mothers of children with an ASD can experience growth in their social network by being a member of parent support groups. Similarly, parents in Altieri and Von Kluge's (2009) study spoke about experiencing enriched relationships including family cohesion and friendships, spousal relationships, and relationships with the child. This suggests that while the impact of ASDs on relationships can appear harmful, co-occurring benefits of improvement in the quality of relationships are also visible.

Bevan-Brown (2004) noted in her study that caregivers become experts on ASD. Through their expertise, as well as the opportunity to increase knowledge about disabilities, new interests and new career pathways were noted as areas of growth. For a few (three participants in the qualitative part of this study), the opportunities to learn more about ASDs and engage in new interests led them to new career opportunities. These participants took the challenges of raising their child with ASD to extend themselves in a meaningful way.

Parents also reported enhanced spirituality. For example, Altieri and Von Kluge's (2009) study elicited talk about how parents had to develop a new meaning of what it meant to be a parent of a child with ASD. One of the most commonly documented gains noted by parents was 'patience' (Altieri & Von Kluge, 2009; Myers et al., 2009; Nurullah, 2013). Parents also reported they had advanced their parenting, problem-solving skills, gained a sense of maturity from the experience of raising a child with an ASD, developed self-awareness and confidence in their ability to manage wider life challenges, and had gone on to advocate on behalf of those with ASD and their families (Altieri & Von Kluge, 2009; Nurullah, 2013).

In conclusion, while the results of this study demonstrate that being a parent of a child with an ASD is a challenging experience, it is noticeable that parents can and do have concurrent positive experiences and growth attributed to the experience of raising their children. Positive experiences included emotions such as love and gratitude, a greater bond with partners, friends, and new opportunities to gain knowledge, interests, career, and spiritual growth.

Studies on the positive experiences or benefits of raising a child with ASD are in their infancy. Thus, it is suggested that parents of children with an ASD can not only protect their wellbeing, but also have positive emotions and encounters, growth in personal and interpersonal skills, relationships, spirituality, and a sense of purpose (Bayat, 2007; Kayfitz et al., 2010; Myers et al., 2009). Despite the challenges faced by parents of children with ASD, some of them show adaptive management and even manage to have positive experiences contributing to better family dynamics (Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña, 2016).

CHAPTER SEVEN

7. Conclusions, Recommendations, and Implications of the Study for Social Work and Social Development

7.1. Conclusions

The study describes the challenges, coping mechanisms, and supports for parents of a child with autism based on a sample from the Joy and Nehemiah Autism Centers in Addis Ababa, Ethiopia. The burden of caring for a child with ASD was strenuous for parents. Findings indicated that initially parents had no or little knowledge about autism and reacted with feelings of relief, shock, denial, loss, grief and sadness and frustration. Parents were overwhelmed with the concern over the future life and career of their children with autism upon the detection of their child's autism. Over half (56.5%) of the parents in this study faced stress, over three quarters (77.7%) faced stigma, and 90% struggled with financial constraints. Thus, parents raising children with ASD are leading a complex life partially due to the stress emanating from the daily hectic schedule and extra responsibilities and duties to manage their children's difficult behavior and functional limitations. As a result, some parents may not pay proper attention to their life partners and other children without disabilities.

Most of the parents were not aware of autism before the diagnosis. This limited knowledge and information reflected a lack of awareness about autism in the community. The limited understanding and wrong perceptions of the causes of autism within society also created additional social burdens. Parents of children with autism experience negative responses from the community in the form of isolation and social stigma. Due to traditionally held beliefs about their children's disability, the parents felt underrated by society as well as their relatives, which

threatened their psychosocial well-being. Therefore, they tend to be isolated and blamed and their participation in social life is limited by virtue of having and caring for a child with autism.

Apart from the above psychosocial crises, the parents faced financial constraints. Autism imposes extra and costly expenses to provide a balanced diet, to cover medical therapies, and to pay for extracurricular activities. The participants agreed that they have incurred extra expenses in an attempt to fulfill their child's needs. Besides the expenses, autism also affects parents' income; a few parents were forced to resign from their jobs, or work fewer hours to care for their children. Thus, autism hinders some parents with respect to work and puts a huge financial burden on the parents that in turn make their lives bitter and full of grief.

Despite the practical caregiving, economic and psychosocial challenges, parents used sundry coping mechanisms to decrease or deal with the burdens. Parents coped through positive and/or negative coping strategies. Positive coping mechanisms included religious coping methods (by engaging in spiritual beliefs, praying, attending church programs and/or bible studies, or taking their children to holy water), acceptance, patience and perseverance, reframing, advocacy, educating oneself and others, and acquiring social supports. These strategies are recommended and encouraged by professionals in the field to help parents better manage their children's developmental disorder and deal with their situations. Though the religious-based coping mechanisms were mostly used by the participants, it was emphasized that parents' acceptance of the situation of their child has a vital role in starting to seek supports and committing themselves to see the progress of their children.

Furthermore, in addition to tapping into their resources, parents are using both formal and informal support systems available in their social environment. The informal support from

spouses, close relatives, extended family members, friends, and neighbors was considered as an essential source of psychosocial help and assistance. Participants of this study also used support from formal organizations (Joy and Nehemiah Autism Centers).

This study revealed that both centers provide parents of a child with autism with various awareness-raising training programs, updated information on autism, and job opportunities for parents struggling financially. The centers also offer their children training to develop self-help skills, free lunch, and transportation (school bus) services. As a result, the parents have observed progress in their children's psychomotor development, and self-supporting skills such as toilet training, brushing teeth, keeping hands clean and sanitized before and after meals eating, independently putting on or off their shoes, and improved sleeping time.

Concerning resources, though there are financial limitations, these organizations are playing a key role in training children with autism and their parents. They have also organized parent support groups and provided a locus for parents to discuss and foster support and share experience among the members. Despite the above services provided by the organizations, some participants reported financial instability as a source of stress in raising their children with autism. These parents need to cover the necessities of their children as do parents nurturing typically developing children. However, the extra needs of a child with autism require a parent to be able to earn and provide more. Parents with financial stability can meet the demands of their children and seem better able to cope with the situation compared to parents that are under financial constraint. To address this challenge several works are yet to be accomplished by the centers, concerned bodies, and stakeholders. Generally, the provision of support from the centers was highly encouraging and helped to reduce the psychosocial pain and suffering of the children with autism and their parents.

In summary, parents raising a child with autism in Addis Ababa are burdened in several ways. Factors that contribute to the challenges are lack of attention from the government; low level of awareness about autism in the community; the lack of knowledge on how to manage the behavioral problems of the children; absence of psychosocial support during and after the diagnosis; availability of limited centers that provide care for children with autism; lack of resources and financial constraints. Therefore, these parents are deserted, overburdened, and highly disenfranchised groups.

To avert these challenges both centers and professionals in the centers are working hand-in-hand with parents to improve the situation. Promisingly, parents experienced positive personal changes that have grown as a byproduct of raising their children and that are expressed in terms of increased positive emotions (love and gratitude), spiritual, and personal development. Hence, thinking from a broader perspective, in our interventions, we can support parents not only to survive but also to flourish and blossom.

Finally, participants have indirectly recommended areas in which systematic improvements would be helpful including greater awareness of autism in the community, governmental supports as well as access to educational and medical services. Increased services are needed; more efficient ways of synchronization between the stakeholders, and funding for respite and financial wellbeing are major among the other needs. Now is the time to move forward to urge improvements in the public's awareness of ASD, and to advocate for policies, programs, and services to effect positive social change for parents and children affected by the disorder. Of course, there is far to go and much work to be done if the lives of these children and parents are to be better.

7.2. Recommendations

Parents of children with ASD were surrounded by the challenges that came along with the diagnosis of their children with autism. In making things complex, lack of government intervention and services were also posed additional responsibility on parents and families of children with ASD. Hence, unless some immediate and feasible measures are taken, the miseries and bitter sentiments of these parents remain unsolved and further trigger them to serious psychosocial and financial turbulences. Therefore, based on the results, findings and conclusions of the study, the following recommendations were outlined and forwarded.

1. ***Awareness-raising, Advocacy, and Policy issues:*** The findings underscored the need to design policies that address the comprehensive burdens of ASD at a national level. Advocacy campaigns should also be established to popularize knowledge and proper care about children with autism so that the public is properly informed on the kind of support they can be provided as a member of society. Thus, federal policymakers must understand and determine the most appropriate programs and intervention services for all individuals with autism and their families. It is necessary to help them design programs that are aimed at addressing the needs and challenges of the parents and their children living with autism, and thereby create a conducive and supportive environment for this vulnerable group.
2. The other key finding of this study postulates that lack of understanding by the public made it difficult for the parents as they felt negatively evaluated by people around them, felt judged and felt stigmatized over time. However, we need to make individuals with autism and their families feel welcome, understood, accepted, and not judged. In doing so, efforts have to be made to educate society about autism. Awareness-raising programs and continuous education geared towards combating stigma and discriminatory practices should be given to teachers, family members as well as the community through conferences and public meetings about

children with autism at all levels of society to reduce challenges emanating from lack of awareness.

3. The larger community at the country level can be addressed through wide-ranging media coverage about autism. The media can also play an important role in educating the community about the need for social acceptance of children with autism and their families by increasing understanding of ASD. Thus, effective coordination among autism centers, schools, Media, and families is needed to enhance the level of awareness, and to promote social inclusion and supports in schools, neighborhoods, and public places.
4. Educational institutions should press their departments and schools to include courses in their curriculum that provide an understanding of autism so that professionals of tomorrow can have better knowledge while assisting parents of children with ASD. In addition, an interdisciplinary approach should be practiced within the educational institutions for example coalition between the school of social work and the department of special needs should be promoted so that both can share knowledge and experiences and stronger effort can be exerted in creating awareness about autism in education, in the public and in service organizations.
5. **Services:** The findings of this study demonstrate that facilities designed to accommodate children with disorders such as autism are not easily accessible to parents. Thus, the service is limited and unsatisfactory compared to the need. On the service provision, the government should try and address the different unmet needs and challenges of these children and their parents by providing proper attention and financial support. Upon diagnosis, an information package should be provided to parents with a list of important phone numbers of professionals and service providers, things to do after receiving the diagnosis, experiences of parents who have recently gone through the same experience, and a list of private special needs schools inclusive of children with autism. In addition, the positive and negative aspects of ASD and

how it impacts the child's development should be conveyed to the family of children with ASD (Murphy & Tierney, 2007).

6. Through establishing specialized medical treatment centers and schools for autism, the government can ensure easy access and enrollment to education and affordable therapeutic and support centers. Therefore, concerned bodies in collaboration with the government, Ministry of Education (MoE), NGOs, and other stakeholders must take the initiative to open other rehabilitation and support centers for children with autism throughout the country. Moreover, despite the importance of respite care, these services are not available. The concerned bodies should work to ensure the availability of respite care and other community-based services. In addition, if there is no help from family and/or parents these vulnerable groups have nowhere to go, so there should be drop-in centers for individuals with autism including those who are unable to lead an independent life in their later adulthood and old age.
7. **Partnership and Collaboration:** Parents of children with autism need societal, governmental, and/or NGO support to minimize stress and increase their coping mechanisms. The limited capacity of the two centers and absence of collaboration among actors working on the issue necessitates partnership and collaboration for better results and access. Consequently, leveraging with health facilities, professional associations, centers, and schools among others is important to provide better support and enhance coping mechanisms.
8. Since religion and spiritual methods are found to be the major coping mechanism by the participants of this study, parent support groups and intervention programs for children with autism and their parent in religious organizations should be prepared. The aim is to help the parents share their experiences, and importantly, to develop a mutual support system beyond the religious-based coping mechanisms (belief in God, prayer, and holy water treatment). Thus, a partnership between religious institutions, governmental institutions, hospitals,

schools, and other related agencies would be imperative to provide therapeutic facilities for children with autism and their parents.

9. The centers need to invest further in creating awareness of autism spectrum disorder among the general public. This is vital to influence the service-seeking behavior of parents and families of children with autism. This has to be complemented, however, with increased service delivery capacity via production of knowledgeable and skilled human resources as well as availability of services in different regions. The centers should work to enhance more on the teachers' qualifications by providing intensive training. Concurrently, the Ministry of Education should also give more attention to the implementation of special needs education programs and the availability of trained teachers.
10. **Research:** Universities, research institutions, and concerned government institutions should encourage researchers and academicians to carry out research in the area of autism and produce policy recommendations to improve the lives of children with autism and their families in demonstrating the implications of autism on economic, social and psychological issues at the household, community and country level. Considering the heterogeneity of Ethiopia, conducting a study in other parts of the country is highly recommended. Further research on parents raising a child with autism residing out of Addis Ababa may provide diverse findings. Overall, considering the inadequacy of studies of ASD in Ethiopia, additional research on the situation of individuals and families impacted by ASD in Ethiopia would contribute to the literature and possibly inform practices leading to improved outcomes for this population.

7.3. Implications of the Study for Social Work and Social Development

The rate of ASD diagnoses is increasing in populations around the globe possibly due to improved diagnostic criteria and tools, better reporting, and availability of services for those with ASD (American Psychiatric Association, 2013; Elsabbagh et al., 2012; WHO, 2013). However, in Ethiopia, the level of awareness, knowledge, and support for individuals with ASD is still very low (Alem et al., 1999; Bakare et al., 2009; Shibrei et al., 2003). Hence, raising a child with ASD is fraught with challenges and can place considerable burden and stress on the parents.

Individual development and experiences throughout the lifespan are greatly affected by their most important environment (Bronfenbrenner, 1979). Focusing on activities at all levels of the environment is relevant to a better understanding of factors affecting the management of ASD and the experiences of parents affected by the disorder (Bernier, Mao, & Yen, 2010). Further, an increased understanding of ASD within different cultural settings is significant to positive outcomes in the lives of individuals affected (Kang-Yi, 2013). The focus for building resilience needs to shift from individuals to environments that can be responsive to parents' needs (Ungar, 2011). Pearlin and Schooler (1978) speak about the deeply rooted problems within society that force vulnerable populations to manage without adequate support: "Coping failures, therefore, do not necessarily reflect the shortcomings of individuals; in a real sense, they may represent the failure of social systems in which the individuals are enmeshed" (p. 18). Family resilience can be better understood when symptoms of distress are linked with stressful contexts (Walsh, 2003). Parents are resilient because they have been driven to adapt due to the additional challenges associated with ASD, a general lack of understanding from others, and inadequate support and resources from the health and education sector.

This research has implications for social work education, research, policy, and practice. Intervening effectively in the lives of children with autism and their parents is not the sole responsibility of any single agency or professional group, but rather is a shared community concern. Social work is a profession that works towards the betterment of vulnerable groups of people. Parents of a child with autism are one of the marginalized groups of people in Ethiopia and these parents are vulnerable to multi-dimensional challenges. As a result, different (a holistic kind of) social work interventions are needed. For example, case management that addresses the issue of a client by considering their social environment should be provided. The client, parents being the center of intervention, interventions should be put in place for the autistic children and their parents by considering the socio-cultural environment including the community, both formal and informal organizations that parents interact with. In such a way, it creates an opportunity to strengthen their support system, to coordinate and utilize the resources in their environment.

Furthermore, professionals need to be in a better position to help parents develop realistic expectations and work towards achievable goals (Hebert & Koulouglioti, 2010). The implications of this study for positive social change include contributing to increased awareness about ASD among educators and other providers working with parents of individuals with ASD, subsequently leading to better services. The insights shared by the participants of this study could provide family members and friends, churches, educators, healthcare professionals, the government, and other members of the community valuable information on how lack of support negatively impacts parents raising children with ASD in Addis Ababa.

According to Bello-Mojeeed et al. (2013), increasing the understanding of the healthcare population regarding the health and psychosocial impact of ASD on parents or caregivers may contribute to improvement in services provided. Thus, a specific practice recommendation of this

study is that it could be used to educate and train educators, healthcare professionals, and other providers working with families of individuals with ASD, to improve their understanding, sensitivity, and empathy that would contribute to the provision of better care to these families through emphasizing possible target areas by planning and advocating for changes in policies and programs and improved services and treatment of those affected by ASD. Therefore, in addition to autistic children and their parents, social work professionals should leap their plan and provide interventions to the whole family and community in a culturally competent way. Hence, putting this into consideration, this research has the following implications for social work education and practice.

7.3.1. Implications for Social Work Education: Awareness raising and Advocacy

One of the goals of Social Work is to promote social change for marginalized groups including parents of children with autism and to highlight the day-to-day challenges faced by these vulnerable groups. Lack of access to appropriate information, both early on and as the child ages, is a significant barrier to adjustment for families of a child with ASD (Turnbull, Turnbull, Erwin, & Soodak, 2006). Even when parents find quality information to address the child's and parents' needs in one developmental phase, they often must start the search over again because the types of information that are required vary over the life span of the child. The Internet offers a wealth of information not previously available to parents, but parents often have difficulty discriminating high-quality information among the overwhelming amount of information that they find online (Carter, 2009). Misinformation about ASD on the web is abundant (Jordan, 2010), and parents can waste precious time.

Parents of a child living with autism are challenged in different ways, including in interacting with their socio-cultural environment. There is a need to create awareness about

autism. The community's reaction to a child with autism has an impact on parents and other family members. To brighten the hope of parents, the community should be the center to bring a change of attitude. Changing the attitudes and perceptions of the community through organizing awareness-raising campaigns in collaboration with different stakeholders should be a main activity in social work education. Creating a public forum and community conversation, preparation of pamphlets, blogging on newspapers and websites can be used as an alternative approaches to reaching the community. At the country level autism awareness can be addressed through extensive media coverage involving government and non-governmental bodies. Thus, nationwide advocacy work in awareness-raising programs should be promoted, including religious institutions. This creates an opportunity to mobilize the community for the care and support of children with autism and their parents.

To recognize the early signs of autism, training is instrumental for nurses, psychologists, social workers, and teachers in daycares, and primary schools. It is critical that red flags are monitored and referrals made to specialists when appropriate. Moreover, the conceptualization of coping mechanisms (resilience) into teachable and learnable skills, suggests that families can be taught to become more resilient through counseling and psycho-education programs.

The UN Convention on the Rights of a Child (1989) indicates that the child, because of his or her physical and mental immaturity, needs special safeguards and care, including appropriate legal protection before and after birth. The long waiting list/time for the enrollment of a child in the center for support is against a child's right. The convention stated a child has a right to education regardless of whether that child has a disability. Social workers must be agents of social justice and advocate for the rights of a child with autism in accessing every service as per their needs.

7.3.2. Implications for Social Policy: Socially structured barriers can inhibit parents and families (Seligman & Darling, 2007). The characteristics of the family's community must be taken into consideration, for example, the availability of public programs, government policies regarding resource allocation, and societal norms (Patterson, 2002). Cumulative stress has the potential to weaken positive coping responses (Walsh, 2006). To increase positive outcomes and foster resilience among parents raising a child on the autism spectrum, the findings of this study point towards identifying and intervening early, raising parents' capabilities and self-efficacy when managing their child's behavioral problems, revitalizing social support, ensuring respectful parent and professional relationships, and channeling resources to where they are most needed. Thus, it is underscored that there is an urgent need to design policies that address the comprehensive burden of parents of a child with ASD.

Therefore, the most important step to tackle the problem of autism is through the development and endorsement of a national policy that emphasizes the well-being of children with autism and their parents. Even though mental health was mentioned in the national health policy of the country, there is a lack of attention to autism. As a result, the development of policy that ensures the responsibility and accountability of all the concerned bodies is needed. According to WHO and MoH (2006), sustainable development of a mental health system can be achieved only if services are based on policy and guided by the action plan. Therefore, Ethiopia needs a policy on the rights and services that should be made available for parents and their children.

7.3.3. Implications for Social Work Practice: Parents need to be adequately supported to nurture their children as they grow to achieve the best outcomes. Parents' coping abilities must not be damaged through poorly resourced, fragmented, or unsuitable service systems. Research

participants indicated the need for more support for parents and better communication from professional agencies. In this study, endeavors were made to shed light on the experiences of parents of children with autism presenting information that may lead to the development of appropriate supports. With increased support from professional agencies, parents would be able to provide better support and care for their children with autism, leading to positive change.

Assessment, referral, and interventions: Social workers play a key role in assessing parental distress, as well as referring families to appropriate mental health services. Since a more resilient parent reports less parental stress, there is a need to focus on programming for families that enhance their coping abilities to readjust with the situations. Osborne, McHugh, Saunders, and Reed (2008) found that high levels of parenting stress counteracted the effectiveness of interventions. Thus, interventions that promote stress management and stress reduction will not only benefit the parent/caregiver's well-being but also directly benefit the child with ASD.

ASD is a complex diagnosis, often requiring interventions by multiple providers and agencies. Many families experience difficulties in identifying the services and support they need, determining where they can find and readily access these services (McLennan et al., 2003). Once services are identified, navigating the service systems requires knowledge, time, and persistence since parents rarely have a care coordinator to assist them through the process. Kogan and colleagues' (2008) claimed that children with ASD were more likely than children with other special health care needs to have unmet needs, and that family with ASD also received fewer family support services. For example, poor access to respite care is a problem that often restricts the family's activities (Bromley et al., 2004). Few providers are trained to care for a child with ASD, and the lack of available respite may lead to community restriction that disconnects the family from broader sources of support. One possible means of addressing this problem is to

increase access to training for care workers on ASD. Murphy and Verden (2013) demonstrated preliminary success in training undergraduate students on characteristics of ASD and behavioral analysis. According to their study, the families were satisfied and provided with better respite care services.

Furthermore, social workers play a critical role in developing interventions that target healthy family functioning. Interventions that are aimed at increasing parents' resilience as a means to decrease parental stress need to focus on providing parents with coping skills needed to directly impact their well-being. Because more than half (56%) of parents in this study scored the highest on the parental distress scale, interventions must incorporate cognitive-behavioral strategies for stress management. The strategies of Cognitive Behavioral Therapy such as "stressful event and physiological reaction self-monitoring, muscle relaxation skills, and modification of cognitions associated with distress" may be useful (Singer, Irvin, & Hawkins, 1988, p. 272). Stress management combined with additional support services has demonstrated clinically significant improvements in levels of parental distress (Singer, Ethridge, & Aldana, 2007). Lecavalier et al. (2006) claimed that behavioral problems were found to be related to caregiver stress more than any other characteristic associated with their child's autism spectrum disorder. Hence, it is crucial to assess parental stress levels and the child's behavioral problems that can inhibit overall family functioning (Rao & Beidel, 2009). Support professionals are in a position to decrease stress and depression, increase parent confidence, and foster resilience through behaviorally-based family intervention programs that teach parents how to effectively manage ASD symptoms (Bitsika et al., 2013).

From the parents' perspectives, practical and specific applications of information, strategies, and skills were seen as critical to managing their child's troublesome behaviors at

home and outside of the home. Parents expressed in their interviews that professionals would explain why their child had troublesome behaviors, but it was equally important for them to know concrete methods for managing those behaviors. It was important to not only know why helped with patience, tolerance, and forgiveness but also to know how to build the necessary skills to manage the behavior effectively. Behavioral management training can give parents workable strategies that both decrease their child's problem behaviors and increase their self-efficacy in managing those behaviors (Sofronoff & Farbotko, 2002). Support for parents as they gain experience and confidence can have a continued positive impact on family well-being. Furthermore, professionals in a supportive role can help parents develop their social networks and link them into larger systems, such as parent support groups, schools, and health services (Kalil, 2003).

Addressing social support needs: Social support can provide the much-needed emotional connection, practical assistance, feedback, and resources for this population at risk. Lack of social support inside and outside of the family contributes to stress levels for mothers and fathers (Hastings, 2003) and increases the likelihood that stressors would correspond to isolation (Dunn et al., 2001). The stressful challenges in these parents' lives can be mediated by strengthening the interrelationships between their family, friends, and community (Walsh, 2003). Of course, parents are "uniquely qualified" to offer support to each other, which benefits both the giver and the receiver and has a transforming effect on the process of coping and adaptation (Kerr & McIntosh, 2000, p. 309). Parent support networks can promote a sense of belonging, a haven to share difficulties, and can improve emotional wellbeing through acceptance and recognition (Altieri & Von Kluge, 2009; Boyd, 2002). Social validation along with skill development can improve personal efficacy (Bandura, 1997). A network of self-sustaining practices is built (Carpenter, 2000) through beneficial advice and emotional support (Carver et al., 1989).

Building respectful parent and professional relationships: Carpenter (2000) argues that when professionals acknowledge the depth of knowledge families' hold about the child and position the family at the heart of service delivery, then a more responsive and respectful partnership develops. Bronfenbrenner (1979, 1986) noted the importance of encouraging mutual trust and reciprocity, working towards common goals and respecting the balance of power for those who act on behalf of the developing person and their well-being. The relationship between parents and professionals should be based on negotiated equality. Parents' viewpoints regarding their child need to be recognized and valued (Stace, 2011) as "the values, knowledge, preferences and cultural perspectives of the family should be respected and evident in services and resources" (New Zealand Ministries of Health and Education, 2008, p. 63).

Relationships that have "mutual trust, a positive orientation, goal consensus between settings, and an evolving balance of power" can better support parents' development (Bronfenbrenner, 1979, p. 212). The recognition that parents are experienced and knowledgeable about their child creates reciprocal and respectful relationships that are "bidirectional" in their nature. Bronfenbrenner (1979) believes that when the child's parents and teachers form a strong relationship, becoming primary triads, then parents can serve as a "catalytic power," enhancing the child's development (p. 211).

A strengths-based approach can promote supportive and trusting relationships between parents and practitioners (Tedeschi & Kilmer, 2005). In conjunction with increasing parents' understanding of their child's development and their ability to parent, intervention, support and counseling should concentrate on the needs of the entire family, especially at critical periods (Bevan-Brown, 2004). For example, programs that include siblings can open communication between family members, strengthen bonds, and promote productive coping strategies (Tsao,

Davenport, & Schmiede, 2012). According to this perspective, parents hold a wealth of knowledge about what does or does not work with their children. They are highly motivated to see their child succeed and their family function well. Professionals that interact with parents with respect for their experience and perspectives, awareness of the high demands associated with raising children with ASD, and the ability to utilize strengths would build trusting relationships.

In Ethiopia, at the country level, there are only two institutions providing care for a child with autism and their parents. Though the two centers are available in the capital city of Ethiopia—Addis Ababa, the number of individuals who need the services (both in and out of Addis Ababa) is increasing over time. Through the eyes of the participants, there is limited service availability, and thus, there is a quest for service coordination, and a need to promote advocacy efforts to increase funding and services. To provide support for parents and their children, schools of social work and social workers need to advocate for the expansion of centers in the country.

Although initiatives are taken by individuals in establishing the centers for children with autism, as an effort to support both children and parents of children with autism, it is still far from reducing the challenges, because efforts are very limited and unsatisfactory compared to the need. Social workers and service-giving agencies especially those working with children should construct programs that can accommodate children with autism and their parents. Therefore, social work professionals are on the front line to lobby these facts, and their involvement should be promoted so that they can advocate for the provision of psychological, social, and economic support for parents of children with autism.

7.3.4. Implications for Research: According to Alston and Bowles (2003), social research is the systematic observation and collection of information to make a decision or to take action. The research participants provided valuable insight (from an emic perspective), on the challenges, coping mechanisms, and the role of support systems in parenting a child with autism. Examining parents' experiences contributed toward understanding how best to support this population in raising a child with autism. The findings and insights the parents shared provide social workers, educators, other professionals, and the general population valuable information on providing support and resources to parents of children with autism.

Autism in the Ethiopian context is understudied. For example, there are no studies and only a few estimates are available on the prevalence of autism. There is a need for future studies to document the statistical data such as the prevalence rate. Furthermore, cross-cultural views of autism and the image created by media will also be important fertile terrain or areas for future research. Thus, a content analysis of representations of ASD in the media and public discourses would be an area to be studied. In addition, experimental research should be conducted to show which types of support are more effective in reducing parental challenges.

Generally, the number of studies directed towards autism in the Ethiopian context is insignificant from a social work perspective. Studies on autism focusing on the family system that incorporates the perspectives of other family members including their siblings need to be conducted to improve the well-being of children with autism and their entire family. Moreover, studies that explore the coping strategies utilized by the parents of children with autism should also be conducted so that social workers can be assisted to capitalize on parent strengths. Since the selection of participants was made through the involvement of the center, further research should be done on parents who are not obtaining support from the organizations/centers. Based on the findings of these studies, it is recommended that social workers should advocate for a policy and additional interventions.

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Appendix-A: Participants Information Sheet and Consent Form

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Participants Information Sheet and Consent Form

Participants Information Sheet

I am Biruk Befkadu, a Ph.D. student at Addis Ababa University, School of Social Work. Currently, I am conducting research as a requirement for Doctoral Education in Social Work and Social Development.

Purpose: The purpose of the study is to examine the *Challenges, Coping Mechanisms and Supports for Parents of Children with Autism in Addis Ababa*. For the success of the study, the cooperation of parents of a child with autism is crucial, and I would like to ask your permission to participate voluntarily in this study. To achieve this objective, I will employ in-depth interviews, key informant interviews, and structured questionnaires as data collection tools.

Benefits of the Study: For your participation in the study, no payment will be granted or no special privilege will be given to you, but your participation enables me to know what I am supposed to investigate. By participating in this study, you will contribute not only to the success of my studies but also for the advancement of knowledge in the area of caring for a child with autism and their parents.

Risks of the Study: There is no potential risk that may cause any harm to the study participant. Once again, your participation in this study is voluntary and except for the time you spend with me, I do not see any risk that you will face by participating in this study.

Rights as a Participant: The interview has an estimated length of one and a half to two hours. Your participation in the study is based on your willingness, and if you have any questions, you have the right to ask. Besides, you may choose to skip any question that is not interesting to you or you may withdraw from this study at any point in time. Your decision will be respected.

Confidentiality: All information, which will be collected during the interview, will be kept confidential and will not be accessible to any third party. To protect the privacy and confidentiality of your response, the information will be treated using a pseudonym and you will not be identified for any reason.

This information and consent form is organized to make sure that you are willing to participate in the study. If you have any questions or concerns, you may contact the researcher by the following telephone number/0911786265 or Co-Advisor, Dr. Debebe Ero, 0911639236. Finally, if you are agreeing to be part of this research, read and confirm by signing the consent form.

Consent Form

By being the participant of this research:

- I consent to the processing of my personal information for the purposes explained to me.
- I understand that I can withdraw from this study at any time without having to give any reasons for doing so (up until December 2020).
- I understand that my identity will remain confidential.
- I agree that the information that I provide can be used for educational or research purposes, including publication. In these publications, my confidentiality and anonymity will be maintained.
- I understand that if I have any concerns or difficulties I can contact the study researcher at the telephone number [0911786265].
- I have read and understood the information sheet and agreed to take part in the study.

Participants Code _____

Signature _____

Appendix-B: In-depth Interview Guide for Parents of a Child with Autism

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In-depth Interview Guide for Parents of a Child with Autism

Dear esteemed participant, this in-depth interview guide is developed for conducting a study in partial fulfillment of Doctoral Education in Social Work and Social Development at Addis Ababa University. The purpose of the study is to examine the challenges, coping mechanisms, and available supports for parents of a child living with autism in Addis Ababa. In this regard, your participation has a valuable contribution to the success of the study. Therefore, I invite you to participate in the study by attending this in-depth interview session and answering the following open-ended questions. **Thank you for your cooperation in advance!**

Interviewee ID. No: _____

Interview Start Time: _____

Interview Venue: _____

Interview End Time: _____

Interview Date: _____

Part-I: Personal/Background Information:

1.1. Pick your Pseudonym: _____

1.2. Age: _____

1.3. Sex: _____

1.4. Marital Status: _____

1.5. Educational Status: _____

1.6. Employment Status: _____

1.7. Where do you live? _____, In which Sub-city? _____, Woreda
_____.

Part–II: Child-related Information

- 2.1. How many children do you have? And which child has a problem of autism?
- 2.2. Your relationship with the child/children with autism (Mother or Father)?
- 2.3. Age of your child living with autism?
- 2.4. At what age was your child diagnosed with autism?
- 2.5. Sex of your child living with autism?
- 2.6. Name of the center providing service? From where/whom have you obtained information about the center?
- 2.7. How much have you waited to get service from the center? _____ Years, _____ Months, _____ Days.
- 2.8. How long have you been receiving services?
- 2.9. The educational level of the child within the center?

Part–III: Main Interview Questions

Part–III: 1) Question related to the Perception and Challenges of Autism on the Parents

- 3.1.1. How do you define or perceive autism? What do you think is the cause of autism?
- 3.1.2. When and how you observed strange behavior of your child and then what you did to address the problem?
- 3.1.3. How do you describe your experiences of raising a child diagnosed with autism?
- 3.1.4. What are the challenges you as a parent faced in raising a child living with autism?
Probe for the major challenge faced by the parents.
- 3.1.5. How do you describe the negative psychological effects that you experienced due to the diagnosis of your child with autism (like Stress, depression, shock, guilt, self-blame... etc.)?
- 3.1.6. What are the major factors that contribute to stress? If any?
- 3.1.7. How do you explain the positive psychological experience in the family because of having a child with autism?
- 3.1.8. How was your participation in social relationships before and after the diagnosis of a child with autism?
- 3.1.9. How do you explain the extended family's reaction to a child diagnosed with autism?

- 3.1.10. How do you describe the community's reaction in public places to a child diagnosed with autism?
- 3.1.11. Is there anything you want to be known by the community?
- 3.1.12. How do you describe your economic situation before and after the diagnosis of a child with autism?
- 3.1.13. Did the diagnosis of your child influence your economic well-being? How? Probe how it affects his/her daily routine, employment situation, etc.
- 3.1.14. What are the major economic challenges the parent faced after the diagnosis of a child with autism? Probe, which cost has increased because of having a child with autism?
- 3.1.15. How are you managing the economic challenge?

Part–III: 2) Question related to the Coping Mechanism of the Parents

- 3.2.1. How did you cope with the challenges of raising a child with autism?
- 3.2.2. What makes raising/caring easier for you and your family?
- 3.2.3. Would you tell me the most used coping mechanism and why?

Part–III: 3) Questions related to the available Support Systems for Parents

- 3.3.1. How do you describe the supports given to you from your marriage partner and other family members?
- 3.3.2. How do you describe the supports given to you from the center?
- 3.3.3. Do you think you are getting adequate support from the center? (Why?)
- 3.3.4. What additional materials/professional support do you need?
- 3.3.5. What challenges have you encountered in getting support from the center?
- 3.3.6. What do you want to be done by different stakeholders (government and NGO) in improving the wellbeing of a child diagnosed with autism and their parents?
- 3.3.7. What advice do you have for parents who have a child newly diagnosed with autism?
- 3.3.8. Lastly, is there anything you would like to tell me before I close the interview?

Thank you for your participation!

Appendix-C: Key Informant Interview Guide for the Founders, Teachers and Medical professionals

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Key Informant Interview Guide for the Founders, Teachers and Medical professionals

Dear esteemed participant, this key informant interview guide is developed for conducting a study in partial fulfillment of Doctoral Education in Social Work and Social Development at Addis Ababa University. The purpose of the study is to examine the challenges, coping mechanisms, and available supports for parents of a child living with autism in Addis Ababa. In this regard, your participation has a valuable contribution to the success of the study. Therefore, I invite you to participate in the study by attending this key informant interview session and answering the following open-ended questions. **Thank you for your cooperation in advance!**

Interviewee ID. No: _____

Interview Start Time: _____

Interview Venue: _____

Interview End Time: _____

Interview Date: _____

Part-I: Personal/Background Information:

1.1. Pick your Pseudonym (optional): _____

1.2. Age: _____

1.3. Sex: _____

1.4. Educational Status: _____

1.5. Field of Study (if any?): _____

1.6. Work Experiences: _____

1.7. Position in the Organization: _____

Part–II: Interview Questions

- 2.1. Can you tell me about how the center was established? Probe what motivates and when it was established.
- 2.2. What do you think are the challenges faced by parents in raising a child with autism?
- 2.3. What do you think helps these parents to cope?
- 2.4. How do parents know about the center and come for the service?
- 2.5. What is the primary purpose/mission of the center?
- 2.6. What are the requirements or criterion of admission in your center?
- 2.7. What types of services are provided for children with ASD in the center?
- 2.8. What are the specific services you provide for parents of a child with ASD in the center? Probe until all services are mentioned. How and why do you choose the services and activities?
- 2.9. How do you describe the center's relationship with the parents of children with ASD?
Probe how the parents are involved in the program-planning and service delivery?
- 2.10. What are your sources of funding to support children with ASD and their parents?
- 2.11. Is there any federal/regional government budget or program to support similar activities? Does the government support you? If yes in what way?
- 2.12. What are the major challenges you face in providing service for children and the parents? Probe the challenges in relation to policy, key stakeholders, human resources, financial resources, equipment, and supplies. How do you think these challenges could be dealt with?
- 2.13. How and in what areas of collaboration do you work with other institutions in Addis Ababa or Ethiopia? Probe which organizations the center is currently working with.
- 2.14. What accomplishment are you most proud of in relation to the center?
- 2.15. What are your goals for the center in the next one to five years?
- 2.16. Is there anything you would like to tell me before I close the interview?

Thank you for your participation!

Appendix-D: Questionnaire for Parents of a Child with Autism

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Questionnaire for Parents of a Child with Autism

Dear esteemed participant, this questionnaire is developed for conducting a study in partial fulfillment of Doctoral Education in Social Work and Social Development at Addis Ababa University. The purpose of the study is to examine the challenges, coping mechanisms, and available supports for parents of a child living with autism in Addis Ababa. In this regard, your participation has a valuable contribution to the success of the study. Therefore, I invite you to participate in the study by answering the subsequent questions. Please circle on the choice of your answer or fill in the blank space following each question. **Thank you for your cooperation in advance!**

Part I: Questionnaire on the Socio-demographic Characteristics of the Respondents

If you don't mind, I'd like to start by asking you a few questions about yourself.					
S. No	Socio-demographic information	Response			SPSS Code
Q101	Age	_____ Years			AGEYRS
Q102	Gender	Male		1	SEX
		Female		2	
Q103	What is your marital status?	Married and living with a partner		1	MARITAL
		Never married		2	
		Separated		3	
		Divorced		4	
		Widowed		5	
		Others (Specify) _____		66	
		NA/No Answer		99	
Q104	What is your religious affiliation?	Orthodox		1	RELGN
		Muslim		2	
		Protestant		3	
		Catholic		4	
		No Religion		5	
		Others (Specify) _____		66	

Q105	What is the highest level of formal education you have completed?	No formal education		1	EDUCLEVL
		Read and Write		2	
		Primary school (grade 1-8)		3	
		High school (grade 9-12)		4	
		Certificate		5	
		Diploma		6	
		B.A/BSc. Degree		7	
		Master and above		8	
Q106	Occupation	Government Employee		1	OCCUP
		NGO Employee		2	
		Private Company Employee		3	
		Trade/Merchant		4	
		Housewife		5	
		Casual labor		6	
		Student		7	
		Others (Specify) _____		66	
Q107	Employment Status	Full-Time		1	
		Part-Time		2	
		Unemployed		3	
Q108	What is your family's total monthly income?	Mother _____			INCOM
		Father _____			
		Specify if any other person is contributing your family income _____, Amount _____			
		Total income _____			
Q109	What is the total number of people (household size) who currently rely on this income (including yourself)?	_____			HHSIZE
Q110	How would you describe your current financial situation?	Routinely unable to purchase sufficient food or other basic necessities		1	FINSIT
		Occasionally unable to purchase sufficient food or other basic necessities		2	
		Sometimes worried about having enough money for the necessities		3	
		Never worry about having enough money for the necessities		4	
		Have more than enough money for necessities and some luxuries		5	
Q111	Has the child conditions caused financial problems for your family?	Yes		1	FINPRO
		No		2	
Q111.1	If yes to Q111, How much percent of your family's monthly income do you think will go to autism treatment	_____			HOWMPER

	and related cost?				
Q112	Place of Residence	Lived more than two years in A.A		1	RESIDENC
		Lived less than two years in A.A		2	
Q113	What is your relationship to the child living with Autism?	Mother		1	RELATIONSH
		Father		2	
		Others (Specify) _____		66	

Part II: Child-related Information/Questions

If you don't mind, I'd like to start by asking you a few questions about your child (name).					
S. No	Child-related Information	Response			SPSS Code
Q201	How many children do you have?	[] []			NUMBCHLD
Q202	Age of your child living with Autism (Name)?	months _____ Years _____			AGEYRS
Q203	What is the gender of your child living with Autism (Name)?	Male		1	SEX
		Female		2	
Q204	What is the birth order of your child with autism?	_____			BIRTHORDR
Q205	When did your child receive the diagnosis?	Months _____, Years _____			DATEDX
Q206	From which center have you obtaining service?	Joy Autism Center		1	CENTERNAM
		Nehemiah Autism Center		2	
Q207	How many months and years have you spent on the waiting list?	_____			WAITINGLST
Q208	Year of stay of your child at the center?	_____			YRSTAY
Q209	The educational level of the child within the center?	_____			CHEDUCLEVL
Q210	What do you think is the most likely cause of your child's ASD?	1. 2.			CAUSECHA
Q211	To help your child with slow development (ASD) to improve, what do you think would help the most?				MOSTHLP

Part III: Parenting Stress Index-Short Form (Abidin, 1995, cited in Soliyana, 2015).

The questions below ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer which comes closest to describing how you feel. YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Please mark the degree to which you agree or disagree with the following statements by filling in the number which best matches how you feel (5 = Strongly Agree, 4 = Agree, 2 = Disagree, 1 = Strongly Disagree) If you are Not Sure, please fill in #3.

S.No	Statements	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
301	I often have the feeling I cannot handle things very well	1	2	3	4	5
302	I find myself giving up more of my life to meet my children's needs than ever expected	1	2	3	4	5
303	I feel trapped by my responsibilities as a parent	1	2	3	4	5
304	Since having this child, I have been unable to do new and different things	1	2	3	4	5
305	Since having this child, I feel that I am almost never able to do things that I like to do	1	2	3	4	5
306	I am unhappy with the last purchase of clothing for myself that I made	1	2	3	4	5
307	There are quite a few things that bother me about my life	1	2	3	4	5
308	Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend)	1	2	3	4	5
309	I feel alone and without friends	1	2	3	4	5
310	When I go to a party, I do not usually expect to enjoy myself	1	2	3	4	5
311	I am not as interested in people as I used to be	1	2	3	4	5
312	I don't enjoy things as I used to	1	2	3	4	5
313	My child rarely does things for me that make me feel good	1	2	3	4	5
314	Sometimes I feel my child doesn't like me and doesn't want to be close to me	1	2	3	4	5
315	My child smiles at me much less than I expected	1	2	3	4	5
316	When I do things for my child, I get the feeling that my efforts are not appreciated very much.	1	2	3	4	5
317	When playing, my child doesn't often giggle or laugh	1	2	3	4	5
318	My child doesn't seem to learn as quickly as most children	1	2	3	4	5
319	My child doesn't seem to smile as much as most children	1	2	3	4	5
320	My child is not able to do as much as I expected	1	2	3	4	5
321	It takes a long time and is very hard for my child to get used to new things	1	2	3	4	5

S.No	Statements	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
322	I feel that I am 1. Not very good at being a parent 2. A person who has some trouble being a parent 3. An average parent 4. A better than average parent 5. A very good parent	1	2	3	4	5
323	I expected to have closer and warmer feelings for my child than I do and this bothers me	1	2	3	4	5
324	Sometimes my child does things that bother me just to be mean	1	2	3	4	5
325	My child seems to cry or fuss more often than me	1	2	3	4	5
326	My child generally wakes up in a bad mood	1	2	3	4	5
327	I feel that my child is very moody and easily upset	1	2	3	4	5
328	My child does a few things which bother me a great deal	1	2	3	4	5
329	My child reacts very strongly when something happened that he/she doesn't like	1	2	3	4	5
330	My child gets upset easily over the smallest things	1	2	3	4	5
331	My child's sleeping or eating schedule was much harder to establish than I expected	1	2	3	4	5
332	I have found that getting my child to do something or stop doing something is: 1. Much harder than I expected 2. Somewhat harder than I expected 3. About as hard as I expected 4. Somewhat easier than I expected 5. Much easier than I expected	1	2	3	4	5
333	Think carefully and count the number of things that your child does that bother you. For example, dawdles, refuses to listen, is overactive, cries, interrupts, fights, whines, etc. Please fill in the number which includes the number of things you counted	1-3	4-5	6-7	8-9	10+
334	There are some things that my child does that really bother me a lot	1	2	3	4	5
335	My child turned out to be more of a problem than I expected	1	2	3	4	5
336	My child makes more demands on me than do most children	1	2	3	4	5

Part IV: Family Interview Schedule-Stigma Scale (FIS-SS)

(Sartorius & Janca, 1996)

S.No	Statements	Not at all (0)	Sometimes (1)	Often (2)	A lot (3)
401	Worried about being treated differently	0	1	2	3
402	Worried other people would find out about it	0	1	2	3
403	Felt the need to hide this problem from people (i.e. your child has problems)	0	1	2	3
404	Helping other people to understand what it is like to have a child with slow development	0	1	2	3
405	Have you made an effort to keep this problem a secret?	0	1	2	3
406	Worried about being avoided	0	1	2	3
407	Explaining to others that (your child) isn't like their picture of "crazy" people	0	1	2	3
408	Worried that people would blame you for his or her problems	0	1	2	3
409	Worried that a person looking to marry would be reluctant to marry into your family	0	1	2	3
410	Worried about taking him or her out	0	1	2	3
411	Felt ashamed or embarrassed about it	0	1	2	3
412	Sought out people who also have a child with similar problems	0	1	2	3
413	Felt grief or depression because of it	0	1	2	3
414	Felt that somehow it might be your fault	0	1	2	3

Part V: F- COPES (McCubbin, Olson, & Larsen, 1991, cited in Soliyana, 2015).Purpose:

The Family Crisis Oriented Personal Evaluation Scales are designed to record effective problem-solving attitudes and behaviors, which families develop to respond to problems or difficulties.

Directions:

First, read the list of response choices one at a time.

Second, decide how well each statement describes your attitudes and behaviors in response to problems or difficulties. If the statement describes your response *very well*, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response. Use the following five-point scale: (5 = Strongly Agree, 4 = Agree, 3 = Not Sure, 2 = Disagree, 1 = Strongly Disagree).

WHEN WE FACE PROBLEMS OR CRISES IN OUR FAMILY, WE RESPOND BY:

S.No	Statements	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
501	Sharing our difficulties with relatives	1	2	3	4	5
502	Seeking encouragement and support from friends	1	2	3	4	5
503	Knowing we have the power to solve major problems	1	2	3	4	5
504	Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
505	Seeking advice from relatives (grandparents, etc)	1	2	3	4	5
506	Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
507	Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
508	Receiving gifts and favors from neighbors (e.g. food, taking in mail...)	1	2	3	4	5
509	Seeking information and advice from the family doctor	1	2	3	4	5
510	Asking neighbors for favors and assistance	1	2	3	4	5
511	Facing the problems “head-on” and trying to get solutions right away	1	2	3	4	5
512	Watching television	1	2	3	4	5
513	Showing that we are strong	1	2	3	4	5
514	Attending church services	1	2	3	4	5
515	Accepting stressful events as a fact of life	1	2	3	4	5

S.No	Statements	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
516	Sharing concerns with close friends	1	2	3	4	5
517	Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
518	Exercising with friends to stay fit and reduce tension	1	2	3	4	5
519	Accepting that difficulties occur unexpectedly	1	2	3	4	5
520	Doing things with relatives (get-togethers, dinners, etc)	1	2	3	4	5
521	Seeking professional counseling and help for family difficulties	1	2	3	4	5
522	Believing we can handle our own problems	1	2	3	4	5
523	Participating in church activities	1	2	3	4	5
524	Defining the family problems in a more positive way so that we do not become too discouraged	1	2	3	4	5
525	Asking relatives how they fell about problems we face	1	2	3	4	5
526	Felling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
527	Seeking advice from a minister	1	2	3	4	5
528	Believing if we wait long enough, the problem will go away	1	2	3	4	5
529	Sharing problems with neighbors	1	2	3	4	5
530	Having faith in God	1	2	3	4	5

Part VI: Family Support Scale/FSS/ (Dunst, Trivette & Jenkins, 2007 cited in Soliyana, 2015).

Listed below are people and groups that often times are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to **your family**. Please **circle** the response that best describes how **helpful** the people and groups have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child (ren)?

S.No	Statements	Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
601	My parents	NA	1	2	3	4	5
602	My spouse or partner's parents	NA	1	2	3	4	5
603	My relatives/kin	NA	1	2	3	4	5
604	My spouse or partner's relative/kin	NA	1	2	3	4	5
605	My spouse or partner	NA	1	2	3	4	5
606	My friends	NA	1	2	3	4	5
607	My spouse or partner's friends	NA	1	2	3	4	5
608	My older child(ren)	NA	1	2	3	4	5
609	Neighbors	NA	1	2	3	4	5
610	Others parents	NA	1	2	3	4	5
611	Co-workers	NA	1	2	3	4	5
612	Parent group members	NA	1	2	3	4	5
613	Social groups/clubs	NA	1	2	3	4	5
614	Church members/minister	NA	1	2	3	4	5
615	My family or child's physician	NA	1	2	3	4	5
616	Early childhood intervention	NA	1	2	3	4	5
617	School/daycare center	NA	1	2	3	4	5
618	Professional helpers (social workers, therapists, teachers, etc)	NA	1	2	3	4	5
619	Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
620	_____						
621	_____						

Thank you for your participation!

Appendix-E: Information Sheet and Consent Form (Amharic Version)

አዲስ አበባ ዩኒቨርሲቲ
ማህበራዊ ሳይንስ ኮሌጅ
የሶሻል ወርክ ትምህርት ቤት
ለጥናት ተሳትፎ የመረጃና የስምምነት/ፈቃድ ቅፅ

የመረጃ ቅፅ

ወድ የጥናቱ ተሳታፊዎች፣

ብሩክ በፍቃዱ እባላለሁ። በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ እና ሶሻል ዴቪሎፕመንት (Social Work and Social Development) ትምህርት ዘርፍ የሶስተኛ ዲግሪ (PhD) ተማሪ ነኝ። በአሁኑ ጊዜ፣ ለሶስተኛ ዲግሪ መመረቄያ የሚሆን ወይም የማሟያ ጥናት በማድረግ ላይ እገኛለሁ።

የጥናቱ አላማ፣ የዚህ ጥናት ዓላማ በአዲስ አበባ ዉስጥ የሚኖሩ ኦቲዝም ያላባቸውን ልጆች የሚያሳድጉ ወላጆች የሚያጋጥሟቸውን ተግዳሮቶች፣ እንዲሁም አሉታዊ ጫና ወይም ተፅዕኖዎችን ለማለፍ የሚጠቀሟቸውን የተለያዩ ዘዴዎች እና ለወላጆች የሚሰጥን ድጋፍ ማጥናት ነው። ይህ ጥናት ይሳካ ዘንድ አስተዋጽዖ ከፍተኛ መሆኑን እየገለፅኩ፤ በፈቃደኝነት ላይ የተመሰረተ የዚህ ጥናት ተሳታፊ እንዲሆኑ በአክብሮትና ሙሉ ትህትና እንድትተባበሩኝ እጠይቃለሁ። ይህን አላማ ለማሳካት የተለያዩ መጠይቆችን በመጠቀም ስለወላጅ እና ልጅ ሁኔታ መሰረታዊ መረጃ እሰበስባለሁ።

ጥናቱ የሚያስገኘዉ ጥቅም፣ የጥናቱ ተሳታፊ በመሆንዎ የሚያገኙት ክፍያ ወይም ልዩ ጥቅም የለም ነገር ግን የእርሶ ተሳትፎ ማጥናት የተፈለኩትን ጉዳዮች በጥልቀት ለመመርመር ይረዳኛል። የኔ ጥናት እንዲሳካ ከማበርከትም በተጨማሪ ኦቲዝም ያላባቸውን ልጆች በሚያሳድጉ ወላጆች ዙረያ ያለዉን እውቀትና ግንዛቤ እንዲጨምር አስተዋፆ ያደርጋሉ።

ስጋት፣ በተሳታፊዎች ላይ የሚያጋጥም ስጋት/አደጋ የለም። ተሳትፎዎ በእርሶ መልካም ፍቃድ ላይ የተመሠረተ ነው። ከእኔ ጋር ከሚያሳልፉት ጊዜ ውጭ በዚህ ጥናት በመሳተፍዎ የሚያገጥምዎት ምንም ዓይነት አደጋ/ስጋት አይኖርም።

የጥናቱ ተሳታፊ መብት፣ ይህ ቃለ መጠይቅ ከአንድ ሰዓት ከሰላሳ ደቂቃ እስከ ሁለት ሰዓት ሊፈጅ የሚችል ነው። ቃለ መጠይቁ የሚካሄደው በእርሶ ሙሉ ፍላጎት ላይ ብቻ ተመሥርቶ ሲሆን የመጠየቅና ማብራሪያ የማግኘት

መብት አለዎት። ከዚህም በተጨማሪ መመለስ የማይፈልጉአቸው ጥያቄዎች ካሉ ማለፍ ይችላሉ ወይም የሚፈልጉትን ጥያቄ ብቻ የመመለስ ነጻነት አለዎት እንዲሁም በየትኛውም ጊዜ ቃለመጠየቁን መቀጠል አልፈልግም ወይም ማቋረጥ እፈልጋለሁ ብለው ካመኑ ማቋረጥ ይችላሉ። ውሳኔዎች የሚከበር ይሆናል።

የቃለ መጠይቁ ሚስጥራዊነት፣ በቃለ መጠይቁ ጊዜ የሚነግሩኝ ሙሉ መረጃ በሚስጥር እንደሚያዝና ከጥናቱ አላማ ውጭ ለሶስተኛ ወገን የማይደርስ ይሆናል። የቃለ መጠይቁን ወይንም የውይይቱን ሚስጥራዊነት ለመጠበቅ የጥናቱ ጽሁፍ በሚቀርብበት ጊዜ መለያ የሚሆን ምልክት ወይም ቁጥር ይሰጠዋል። ስለዚህ ማንነትዎ በማንኛውም ሁኔታ ለማንም ግልጽ አይደረግም።

ይህ የስምምነትና ፈቃድ ቅፅ የተዘጋጀው ፈቃደኛ መሆንዎን ለማረጋገጥ ነው። ግልጽ ያልሆነልዎት ጥያቄ ቢኖር ወይም በጥናቱ ላይ ተጨማሪ ማብራሪያ ከፈለጉ፣ እኔን የጥናቱን አድራጊ ብሩክ በፍቃዱ በስልክ ቁጥር +251-911-786265፣ ወይንም የጥናቱን አማካሪ ዶ/ር ደበበ ኤኖን በስልክ ቁጥር +251-911-639236፣ ማነጋገር ይችላሉ። በመጨረሻም፣ በተጠቀሱት ሁኔታዎች ተስማምተው በጥናቱ ላይ ለመሳተፍ ፈቃደኛ ከሆኑ ይህንን ቅፅ በመፈረም እንዲያረጋግጡልኝ በትህትና እጠይቃለሁ።

የስምምነት ዉል/ቅፅ

በዚህ ጥናት ተሳታፊ በመሆኔ፣

- ግላዊ የሆነ መረጃ በጠናቱ ውስጥ እንዲካተት ፈቃደኛ መሆኔን ለማረጋገጥ እወዳለሁ።
- በየትኛውም ጊዜ ቃለመጠየቁን መቀጠል አልፈልግም ወይም ማቋረጥ እፈልጋለሁ ብዬ ካመንኩ ማቋረጥ እችላለሁ (እሰከ ታህሳስ 2013 ዓ.ም. ብቻ)።
- ማንነቴ በማንኛውም ሁኔታ ለማንም ግልጽ አይደረግም።
- ጥናቱ ለትምህርታዊ አላማ ብቻ እንደሚፈለግና ጽሁፉ በሚቀርብበትም/በሚታተምበትም ጊዜ የቃለመጠይቁ ወይንም የውይይቱ ሚስጥራዊነት የተጠበቅ እንደሚሆን ተስማምቻለሁ።
- ግልጽ ያልሆነኝ ነገር ወይም በጥናቱ ላይ ተጨማሪ ማብራሪያ ብፈለግ፣ የጥናቱን አድራጊ አቶ ብሩክ በፍቃዱን በስልክ ቁጥር +251-911-786265፣ ማነጋገር እችላለሁ።
- ይህን የስምምነትና መረጃ ቅፅ አንብቤ በመረዳት ጥናቱ ላይ ለመሳተፍ ፈቃደኛ መሆኔን አረጋግጣለሁ።

የጥናቱ ተሳታፊ መለያ _____

ፊርማ _____

Appendix-F: In-depth Interview Guide for Parents of a Child with Autism (Amharic Version)

አዲስ አበባ ዩኒቨርሲቲ ማህበራዊ ሳይንስ ኮሌጅ የሶሻል ወርክ ትምህርት ቤት

ከአቲዝም ጋር ለሚኖሩ የህጻናት ወላጆች የተዘጋጀ ጥልቅ ቃለመጠይቅ

ውድ ተሳታፊ ይህ መጠይቅ የተዘጋጀው በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ እና ሶሻል ዴቪሎፕመንት (Social Work and Social Development) ትምህርት ዘርፍ ለሶስተኛ ዲግሪ መመረቂያ ወይም የማሟያ ጥናት ለማድረግ ነው። የጥናቱም ዓላማ ተግዳሮቶችን፣ እንዲሁም አሉታዊ ጫና ወይም ተፅዕኖዎችን ለማለፍ የሚጠቀሟቸውን የተለያዩ ዘዴዎች እና ለወላጆች የሚሰጥን ድጋፍ ማጥናት ነው። በዚህ ረገድ የእርስዎ ተሳትፎ ለጥናቱ ስኬት ከፍተኛ አስተዋጽኦ አለው። ስለዚህ በሚደረገው ጥልቅ የቃለመጠይቅ ሂደት ላይ እንዲሳተፉ እየጋበዝኩ ቀጥሎ የተዘረዘሩትን ክፍት ጥያቄዎች እንዲመልሱ እጠይቃለሁ። **ለትብብርዎት በቅድሚያ አመሰግናለሁ።**

የቃለመጠይቅ መለያ ቁጥር: _____ ቃለመጠይቁ የተጀመረበት ሰዓት: _____
የቃለመጠይቅ ቦታ: _____ ቃለመጠይቁ የተጠናቀቀበት ሰዓት: _____
የቃለመጠይቅ ቀን: _____

ክፍል አንድ: የግል/ቅድመ-ታሪክ መረጃ

- 1.1 እባኩ (ከእዉነተኛ ስሞ ዉጭ) አርሶን ሊወክል የሚችል ስም ይምረጡሊኝ: _____
- 1.2 ዕድሜ: _____
- 1.3 ፆታ: _____
- 1.4 የጋብቻ ሁኔታ: _____
- 1.5 የትምህርት ደረጃ: _____
- 1.6 የቅጥር/የስራ ሁኔታ: _____
- 1.7 የመኖሪያ ቤት: _____ ክፍለ ከተማ? _____ ወረዳ? _____

ክፍል ሁለት፡ ከልጅ ጋር የተያያዘ መረጃ

- 2.1 ምን ያህል ልጆች አለዎት? የትኛው/ዋ ልጅ የኦቲዝም ችግር አለበት/ባት?
- 2.2 ከልጅ ጋር ያለዎት ግንኙነት (እናት ወይም አባት)?
- 2.3 በኦቲዝም ተጠቂ የሆነ ህጻን ዕድሜ?
- 2.4 ኦቲዝም የተገኘበት/ባት በምን ያህል ዕድሜ ነው?
- 2.5 ከኦቲዝም ጋር ያለ/ች ልጅ ፆታ?
- 2.6 አገልግሎት እየሰጠዎ ያለ ማዕከል ስም? ስለ ማዕከሉ መረጃ ያገኙት ከማን/ከየት ነው?
- 2.7 ከማዕከሉ አገልግሎት ለማግኘት ምን ያህል ጊዜ ጠብቀዋል? _____ ዓመት፣ _____ ወራት፣ _____ ቀናት።
- 2.8 የአገልግሎቱ ተጠቃሚ የሆኑት ለምን ያህል ጊዜ ነው?
- 2.9 በማዕከሉ ውስጥ የህጻኑ የትምህርት ደረጃ?

ክፍል ሶስት፡ ዋና የቃለመጠይቅ ጥያቄዎች

ክፍል ሶስት፡ 1) በኦቲዝም ተግዳሮት እና የወላጅ ግንዛቤ ላይ የተዘጋጁ ጥያቄዎች

- 3.1.1 ኦቲዝምን እንዴት ይገነዘቡታል ወይም ይገልጹታል? የኦቲዝም መንስኤ ምን ይመስልዎታል?
- 3.1.2 መቼና እንዴት ነገር በልጅ ላይ አዲስ ባህሪ የተመለከቱት? ችግሩን ለመፍታት ምን አድርገዋል?
- 3.1.3 ኦቲዝም ያለበትን ህጻን የማሳደግ ተሞክሮትን እንዴት ይገልጹታል?
- 3.1.4 የኦቲዝም ችግር ያለበትን ህጻን ለማሳደግ ያጋጠመዎት ፈተናዎች ምን ምንድን ናቸው? እንደ ወላጅ ያጋጠሙ ዋና ዋና ችግሮችን ይግለጹ።
- 3.1.5 ልጅዎ ኦቲዝም ችግር ስለተስተዋለበት አሉታዊ የስነ-ልቦና ተጽእኖዎችን እንዴት ይገልጹታል? (ጭንቀት፣ ድብርት፣ ድንጋጤ፣ ሀዘን፣ ራስን መውቀስ ወዘተ... እንዴት ይገልጻሉ)?
- 3.1.6 ለውጥረት አስተዋጽኦ የሚያደርጉ ዋና ዋና ጉዳዮች ምን ምን ናቸው? ካለ ቢገልጹኝ?
- 3.1.7 በቤተሰብ ላይ የሚፈጥረው አዎንታዊ የስነ-ልቦና ተሞክሮ እንዴት ይገልጹታል?
- 3.1.8 ኦቲዝም በምርመራ ከመነገኛ በፊት እና በኋላ ያሉዎትን የማህበራዊ ግንኙነት እንዴት ይገልጹታል?
- 3.1.9 በኦቲዝም ተጠቂ ህጻን ላይ ያለውን የቤተሰብ ምላሽ ወይም ግብረመልስ እንዴት ይገልጹታል?
- 3.1.10 የኦቲዝም ችግር ያለበትን ልጅዎን ይዘው ህዝብ በተሰበሰበበት ቦታ ሲገኙ የማህበረሰቡ ምላሽ/ግብረመልስ ምን ይመስላል?
- 3.1.11 በማህበረሰቡ እንዲታወቅ የሚፈልጉት ጉዳይ አለ?
- 3.1.12 የእርሶን ኢኮኖሚ ሁኔታ ከኦቲዝም በፊት እና በኋላ እንዴት ይገልጹታል?

3.1.13 የልጅዎ በኦቲዝም መጠቃት በኢኮኖሚዎ ላይ የፈጠረው ተፅእኖ አለ? ማለትም በለት ተጸላት ስራ ላይ፤

በቅጥር ሁኔታ ላይ ወዘተ. . . ያመጣው ተጽእኖ ካለ ቢያብራሩሊኝ?

3.1.14 በልጅዎ ላይ ኦቲዝም ከተገኘ በኋላ የፈጠረው ዋና የኢኮኖሚ ፈተናዎች ምን ምን ናቸው? በልጅዎ ኦቲዝም

ምክኒያት ያጋጠመ የወጪ መናገር አለ? ካለ የምን ወጪ?

3.1.15 የኢኮኖሚያዊ ፈተናዎችን እንዴት እየተቆጣጠሩት/እየተቋቋሙት ነው?

ክፍል ሶስት 2) ወላጆች አሉታዊ ጫና ወይም ተፅዕኖዎችን ለማለፍ የሚጠቀሟቸውን ዘዴዎች

አስመልክቶ የቀረበ ጥያቄ

3.2.1 ከኦቲዝም ጋር ያለ/ች ህጻንን በማሳደግ ሂደት የሚገጥሞትን ችግር/ፈተና ለመፍታት

የሚጠቀሙትን ዘዴ ቢያብራሩልኝ?

3.2.2 ልጅዎን ለማሳደግ/ለመንከባከብ፤ ለቤተሰብዎ እና ለእርስዎ ቀላል እንዲሆን ያደረገው ዘዴ ምንድን ነው?

3.2.3 ችግሩን ለመቋቋም የረዳዎትን ዋና/ተደጋጋሚ ዘዴ ሊነግሩኝ ይችላሉ? እና ለምን?

ክፍል ሶስት 3) ለወላጅ ድጋፍ አማራጮችን አስመልክቶ የቀረበ ጥያቄ

3.3.1 ከሌሎች የቤተሰብ አባላት ወይም የትዳር አጋር የሚሰጥዎትን ድጋፍ እንዴት ይገልጹታል?

3.3.2 ከማዕከሉ የሚሰጥዎትን ድጋፍ እንዴት ይገልጹታል?

3.3.3 ከማዕከሉ በቂ ድጋፍ እያገኙ እንዳለ ይሰማዎታል? ለምን?

3.3.4 የሚያስፈልግዎት ተጨማሪ ቁሳዊ/ሙያዊ ድጋፍ አለ?

3.3.5 ከማዕከሉ ድጋፍ በማግኘት ሂደት ያጋጠመዎት ፈተና አለ?

3.3.6 ከኦቲዝም ጋር ለሚኖሩ ልጆች ወይም ወላጆች ድጋፍ ለማሻሻል በተለያዩ አጋር አካላት (መንግስታዊ እና

መንግስታዊ ያልሆኑ ድርጅቶች) ምን እንዲሰሩ ይፈልጋሉ?

3.3.7 አዲስ በኦቲዝም ተጠቂ ለሆኑ የህጻን ወላጆች ምን ምክር የስተላልፋሉ?

3.3.8 በመጨረሻም ቃለመጠይቁን ከማጠናቀቁ በፊት ሊነግሩኝ የሚፈልጉት ጉዳይ አለ?

ለተሳትፎዎ ከልብ አመሰግናለሁ!

Appendix-G: Key Informant Interview Guide for Founders of the Centers, Teachers and Medical professionals (Amharic Version)

አዲስ አበባ ዩኒቨርሲቲ ማህበራዊ ሳይንስ ኮሌጅ የሶሻል ወርክ ትምህርት ቤት

ማዕከሉን ለቋቋሙ ሰዎች፤ መምህራንና ለህክምና ባለሙያዎች የተዘጋጀ ቃለመጠይቅ

ውድ ተሳታፊ ይህ መጠይቅ የተዘጋጀው በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ እና ሶሻል ዴቪሎፕመንት (Social Work and Social Development) ትምህርት ዘርፍ ለሶስተኛ ዲግሪ መመረቂያ ወይም የማሟያ ጥናት ለማድረግ ነው። የጥናቱም ዓላማ ተግዳሮቶችን፣ እንዲሁም አሉታዊ ጫና ወይም ተፅዕኖዎችን ለማለፍ የሚጠቀሟቸውን የተለያዩ ዘዴዎች እና ለወላጆች የሚሰጥን ድጋፍ ማጥናት ነው። በዚህ ረገድ የእርስዎ ተሳትፎ ለጥናቱ ስኬት ከፍተኛ አስተዋጽኦ አለው። ስለዚህ በሚደረገው ጥልቅ የቃለመጠይቅ ሂደት ላይ እንዲሳተፉ እየጋበዝኩ ቀጥሎ የተዘረዘሩትን ክፍት ጥያቄዎች እንዲመልሱ እጠይቃለሁ። **ለትብብርዎ በቅድሚያ አመሰግናለሁ።**

የቃለመጠይቅ መለያ ቁጥር: _____ ቃለመጠይቁ የተጀመረበት ሰዓት: _____
የቃለመጠይቅ ቦታ: _____ ቃለመጠይቁ የተጠናቀቀበት ሰዓት: _____
የቃለመጠይቅ ቀን: _____

ክፍል አንድ: የግል/ቅድመ-ታሪክ መረጃ

- 1.1 እባክ (ከእዚህ ቀደም ጋር) አርሶን ሊወክል የሚችል ስም ይመረጡኋል: _____
- 1.2 ዕድሜ: _____
- 1.3 ፆታ: _____
- 1.4 የትምህርት ደረጃ: _____
- 1.5 የትምህርት አይነት: _____
- 1.6 የስራ ልምድ (በአመት): _____
- 1.7 የስራ ድርሻ/ሀላፊነት: _____

ክፍል ሁለት፡ የቃለመጠይቅ ጥያቄዎች

- 2.1 ይህ ማዕከል እንዴት ሊመሰረት እንደቻለ ሊነግሩኝ ይችላል? እንዲመሰረት ምን ምን ምክኒያቶች ነበሩ እና መቼ እንደተመሰረተ ቢገልጹልኝ?
- 2.2 ከኦቲዝም ጋር የሚኖሩ ህጻናትን የሚያሳድጉ ወላጆች ምን አይነት ፈተናዎች ያጋጥሟቸዋል ብለው ያስባሉ?
- 2.3 ወላጆች ችግሩን ለመቋቋም ያስቻላቸው ዘዴ ዬትኛው ነው ብለው ያስባሉ?
- 2.4 ወላጆች ከማን እና እንዴት መረጃ አግኝተው ለአገልግሎት ወደ ድርጅታችሁ ይመጣሉ?
- 2.5 የማዕከሉ ተቀዳሚ ተልዕኮ/ዓላማ ምንድን ነው?
- 2.6 ከማዕከሉ አገልግሎት ለማግኘት ምን ምን መስፍርቶች መሟላት አለባቸው?
- 2.7 በማዕከሉ ከኦቲዝም ጋር ለሚኖሩ ህጻናት የሚሰጡ አገልግሎቶች ምን ምንድን ናቸው?
- 2.8 በማዕከሉ ከኦቲዝም ጋር ለሚኖሩ የህጻናት ወላጆች የሚሰጡ አገልግሎቶች ምን ምንድን ናቸው? ያሉትን አገልግሎቶች በሙሉ ይግለጹ። ለምን እና እንዴት እነዚህን አገልግሎቶች እና ተግባሮች ሊመርጡ እንደቻሉ ቢግለጹልኝ?
- 2.9 ከኦቲዝም ጋር ለሚኖሩ የህጻናት ወላጆች ጋር ያለውን የማዕከሉ ግንኙነት እንዴት ይገልጹታል? የወላጆችን ተሳትፎ በእቅድ እና አገልግሎት አሰጣጥ ላይ ስላለው ሁኔታ ቢግልጹኝ?
- 2.10 ከኦቲዝም ጋር ለሚኖሩ ህጻናትና ወላጆቻቸው አገልግሎት ለማቅረብ የፋይናንስ/የገንዘብ ምንጭ ወይም ድጋፍ በዋናነት ከምን/ከማን ነው የሚገኙት?
- 2.11 አገልግሎቱን ለማቅረብ፣ ከፌደራል ወይም ከክልል መንግስት የበጀት የድጋፍ ይደረግላችኋል? መንግስት ይደግፋችኋል? አዎ ከሆነ በምን መንገድ?
- 2.12 ለህጻናት እና ለወላጆች ዲጋፍ በማቅረብ ሂደት ያሟያጋጥሙ ዋና ዋና ፈተናዎች ምን ምን ናቸው? ከፖሊሲ ጋር ተያይዞ ያለ ፈተና፣ የቁልፍ አጋር አካላት፣ የሰው ሀይል፣ የፋይናንስ ምንጭ፣ ቁስ እና ከየተለያዩ መሳሪያዎች አቅርቦት አንፃር? እነዚህ ፈተናዎች እንዴት ሊቀረፉ ይችላሉ ብለው ያስባሉ?
- 2.13 በኢትዮጵያ ወይም በአዲስ አበባ ካሉ ሌሎች ተቋማት ጋር ተባብሮ የመስራት ሁኔታን ቢገልጹኝ? በአሁኑ ሰዓት ከየትኛው ድርጅት ጋር በምን ዙሪያ እየሰሩ እንደሆነ ቢያሳውቁኝ?
- 2.14 ከማዕከሉ ጋር ተያይዞ ስኬታማና የምክራብ ተገባር ነው ብለው የሚገልጹት ጉዳይ አለ?
- 2.15 ከሚቀጥለው አንድ ዓመት እስከ አምስት ዓመታት ማዕከሉን የት ወይም ምን ላይ ለማድረስ ግብ ይዘዋል?
- 2.16 በመጨረሻም ቃለመጠይቁን ከማቆሚያ በፊት ሊነግሩኝ የሚፈልጉት ማንኛውም ጉዳይ አለ?

ለተሳትፎዎ አመሰግናለሁ!

Appendix-H: Questionnaire for Parents of a Child with Autism (Amharic Version)

አዲስ አበባ ዩኒቨርሲቲ ማህበራዊ ሳይንስ ኮሌጅ የሶሻል ወርክ ትምህርት ቤት

ከአቲዝም ጋር ለሚኖሩ የህጻናት ወላጆች የተዘጋጀ መጠይቅ

ውድ ተሳታፊ ይህ መጠይቅ የተዘጋጀው በአዲስ አበባ ዩኒቨርሲቲ በሶሻል ወርክ እና ሶሻል ዴቪሎፕመንት (Social Work and Social Development) ትምህርት ዘርፍ ለሶስተኛ ዲግሪ መመረቂያ ወይም የማሟያ ጥናት ለማድረግ ነው። የጥናቱም ዓላማ ተግዳሮቶችን፣ እንዲሁም አሉታዊ ጫና ወይም ተፅዕኖዎችን ለማለፍ የሚጠቀሟቸውን የተለያዩ ዘዴዎች እና ለወላጆች የሚሰጥን ድጋፍ ማጥናት ነው። በዚህ ረገድ የእርስዎ ተሳትፎ ለጥናቱ ስኬት ከፍተኛ አስተዋጽኦ አለው። ስለዚህ በሚደረገው የቃለመጠይቅ ሂደት ላይ እንዲሳተፉ እየጋበዝኩ ቀጥሎ የተዘረዘሩትን ጥያቄዎች በሚመርጡት ምርጫ ላይ በማክበብ ወይም በጥያቄዉ ፊት ለፊት በሚገኝ በባዶ ቦታ ላይ በመሙላት እንዲመልሱ እጠይቃለሁ። **ለትብብርዎት በቅድሚያ አመሰግናለሁ።**

ክፍል አንድ፡ የመልስ ሰጪ የግል መረጃ መጠይቅ

ፍቃደኛ ከሆኑ ስለእርስዎ የተወሰነ በመጠየቅ ልጅምር			
ተ/ቁ.	ግላዊ መረጃ	መልስ	
ጥ101	ዕድሜ	_____ ዓመት	
ጥ102	ፆታ	ወንድ	1
		ሴት	2
ጥ103	የጋብቻ ሁኔታ?	ያገባች እና ከአጋር ጋር እየኖረች ያለች	1
		ፈጽሞ ያላገባች	2
		የተለያየች	3
		የፈታች	4
		አግብቶ/ታ የሞተበት/ችበት	5
		ሌላ ካለ ይግለጹ _____	66
		መልስ መስጠት አልፈልግም	99
ጥ104	ኃይማኖትዎ ምንድን ነው?	ኦርቶዶክስ	1
		ሙስሊም	2
		ፕሮቴስታንት	3
		ካቶሊክ	4
		ኃይማኖት የለኝም	5
		ሌላ ካለ ይግለጹ _____	66
ጥ105	የደረሱበት ከፍተኛ የመደበኛ ትምህርት ወይም ያጠናቀቁት ትምህርት ደረጃ?	መደበኛ ትምህርት ያልተማረ/ች	1
		ማንበብና መጻፍ	2
		1ኛ ደረጃ ት/ት (ክፍል 1-8)	3

		2ኛ ደረጃ ት/ት (ክፍል 9-12)		4
		የምስክር ወረቀት ሰርተፍኬት		5
		ዲፕሎማ		6
		የመጀመሪያ ዲግሪ በማህበራዊ ወይም በተፈጥሮ ሳይንስ		7
		ማስተርስ ዲግሪ እና ከዛ በላይ		8
ጥ106	የሥራ ሁኔታ	መንግስታዊ ድርጅት		1
		መንግስታዊ ያልሆነ ድርጅት		2
		የግል ኩባንያ		3
		ነጋዴ		4
		የቤት እመቤት		5
		ጊዜያዊ/የቀን ሥራ		6
		ተማሪ		7
		ሌሎች ካሉ ይግለጹ _____		66
ጥ107	የቅጥር ሁኔታ	ሙሉ ጊዜ		1
		በትርፍ ጊዜ		2
		ያልተቀጠረ		3
ጥ108	የቤተሰብ ወርሀዊ ገቢ ምን ያህል ነው?	የእናት _____		
		የአባት _____		
		ለቤተሰብ ገቢ የሚያበረክት ልላ ስዉ አለ? _____ የብር መጠን _____		
		ጠቅላላ ገቢ _____		
ጥ109	እርስዎን ጨምሮ በዚህ ገቢ የሚተዳደሩ የቤተሰብ አባላት ብዛት ስንት ናቸው?	_____		
ጥ110	የእርስዎን ወቅታዊ የፋይናንስ ሁኔታ እንዴት ይገልጻሉ?	በቂ ምግብ ወይም ሌሎች መሰረታዊ ፍላጎቶችን መግዛት አለመቻል		1
		በአሁኑ ሰዓት በቂ ምግብ ወይም ሌሎችን መግዛት አለመቻል		2
		ለሚያስፈልገን ነገር በቂ ገንዘብ ያለመኖር		3
		ለሚያስፈልጉን ጉዳዮች ብዙም አለመጨናነቅ		4
		ከሚገባው በላይ በቂ የሆነ እና ለቅንጦት በቂ የሆነ አቅም		5
ጥ111	የልጅዎ በኦቲዝም መጠቃት በኢኮኖሚ ላይ የፈጠረው ተፅእኖ አለ?	አዎ		1
		አይ		2
ጥ111.1	ለጥያቄ 111 አዎ ከሆነ ምን ያህል እጅ (%) ከቤተሰቡ ወርሀዊ ገቢ ለኦቲዝም ሕክምና እና ተያያዥ ወጪ ይወጣል ብለው ይገምታሉ?	_____		
ጥ112	የመኖሪያ ቦታ	በአዲስ አበባ ውስጥ ከሁለት (2) ዓመት በላይ የኖረ		1
		ከሁለት (2) ዓመት በታች በአዲስ አበባ ውስጥ የኖረ		2
ጥ113	ከኦቲዝም ጋር ከሚኖር ልጅ ጋር ያለዎት የዝምድና ግንኙነት	እናት		1
		አባት		2
		ልላ ከሆነ ይግለጹ _____		66

ክፍል ሁለት፡ ክልጅዎ ጋር ተያያዥነት ያለው መረጃ/ጥያቄ

ፍቃደኛ ከሆኑ የልጅዎትን ስም በመጠየቅ ልጅዎር			
ተ/ቁ.	ክልጅ ጋር የተገናኘ መረጃ	መልስ	
ጥ201	ስንት ልጅ አለዎት?	[] []	
ጥ202	ከአቲዝም ጋር የሚኖር ልጅ ዕድሜ (ስም)	_____ ዓመት _____ ወር	
ጥ203	ከአቲዝም ጋር የሚኖር ልጅ (ስም) ፆታ	ወንድ	1
		ሴት	2
ጥ204	ከአቲዝም ጋር የሚኖር ልጅ በቤተሰብ ውስጥ ስንተኛ ልጅ ነው?	_____	
ጥ205	ልጅዎ ተመርምሮ አቲዝም እንዳለበት/ባት የተረጋገጠው መቼ ነው?	_____ ዓመት _____ ወር	
ጥ206	አገልግሎት የሚያገኙት ከየትኛው ማዕከል ነው?	ከጆይ የአቲዝም ማዕከል	1
		ከነህምያ የአቲዝም ማዕከል	2
ጥ207	አገልግሎቱን ለማግኘት ምን ያህል ወር ወይም ዓመት ጠብቀዋል?	_____ ወር _____ ዓመት	
ጥ208	ልጅዎ ከማዕከሉ አገልግሎት ማግኘት ከደመረ/ች ምን ያህል ጊዜ ሆነ?	_____ ወር _____ ዓመት	
ጥ209	በማዕከሉ ውስጥ የልጅዎ የትምህርት ደረጃ?	_____	
ጥ210	የልጅዎ አቲዝም መንስኤ ምንድን ነው ብለው ያስባሉ?	1. 2.	
ጥ211	የልጅዎን ዝግመታዊ የሆነ ሂደት ለማሻሻል ምን መደረግ እንዳለበት ያስባሉ?		

ክፍል ሶስት፡ የወላጅ ጫና ማሳያ-አጭር ቅፅ (Soliyana, 2015).

ተ/ቁ.	ዝርዝር	በጣም አልስማማም	አልስማማም	አርግጦኛ አይደለሁም	እስማማለሁ	በጣም እስማማለሁ
301	ብዙ ጊዜ ነገሮችን በአግባቡ ማስተናገድ እንደማልችል ይሰማኛል	1	2	3	4	5
302	ከገመትኩት በላይ ህይወቴን የልጄን ፍላጎት ለሚሟላት ሰጥቻለሁ	1	2	3	4	5
303	ወላጅ በመሆኔ ባሉብኝ ኃላፊነቶች እንደታሰርኩ ያህል ይሰማኛል	1	2	3	4	5
304	ይሄንን ልጄን ከወለድኩት ጊዜ ጀምሮ አዳዲስና ለየት ያሉ ነገሮችን ለመስራት አልቻልኩም	1	2	3	4	5
305	ይሄንን ልጄን ከወለድኩበት ጊዜ ጀምሮ መሥራት የምወዳቸውን ነገሮች በጭራሽ ማድረግ እንዳልቻልኩ ይሰማኛል	1	2	3	4	5
306	በቅርብ ለራሴ በገዛሁት ልብስ ደስተኛ አይደለሁም	1	2	3	4	5
307	ስለ ህይወቴ የሚያሳስቡኝ ጥቂት ነገሮች አሉ	1	2	3	4	5
308	ይህንን ልጅ በመውለዳችን ምክንያት በእኔና በባለቤቴ መሀል ያለው ግንኙነት ከጠበቅሁት በላይ ችግሮች ገጥመውታል	1	2	3	4	5
309	ብቸኛ እና ጓደኛ አልባ እንደሆንኩ ይሰማኛል	1	2	3	4	5
310	ወደ መዝናኛ ቦታ ስሄድ በአብዛኛው ራሴን ለማዝናናት አላስብም	1	2	3	4	5
311	በፊት ወደ ሰዎች ያለኝን ፍላጎት ያህል አሁን የለኝም	1	2	3	4	5
312	ነገሮችን እንደ ቀድሞው አልዝናናባቸውም	1	2	3	4	5
313	ልጄ አልፎ አልፎ ብቻ ለእኔን የሚያስደስቱኝን ነገሮችን ያደርግልኛል	1	2	3	4	5
314	አንዳንዴ ልጄ እንደማይወደኝና ሊቀርበኝ እንደማይፈልግ ይሰማኛል	1	2	3	4	5
315	ልጄ የሚያሳየኝ ፈገግታ ከምጡብቀው እጅግ ያነሰ ነው	1	2	3	4	5
316	ለልጄ አንዳንድ ነገሮችን የማድረግ ተነሳሽነቴ/ጥረቴ ብዙም አይበረታታም	1	2	3	4	5
317	በጨዋታ ላይ ልጄ ብዙም አይፈነድቅም/አይስቅም	1	2	3	4	5
318	ልጄ እንደ ብዙዎቹ ልጆች በፍጥነት የሚማር አይመስልም	1	2	3	4	5
319	ልጄ የብዙዎችን ልጆች ያህል ፈገግታ የሚያሳይ አይመስልም	1	2	3	4	5
320	ልጄ የምጡብቀውን ያህል መስራት አይችልም	1	2	3	4	5
321	ልጄ አዳዲስ ነገሮችን ለመማር በጣም ይከብደዋል፣ ረጅም ጊዜም ይፈጅበታል	1	2	3	4	5
322	እኔ ይህን እንደሆንኩ ይሰማኛል 1. በጣም ጥሩ ወላጅ 2. ደህንኛ ከሚባል ወላጅ የተሻልኩ 3. መካከለኛ ወላጅ 4. ወላጅ መሆን በመጠኑም ቢሆን የከበደው ሰው 5. ጥሩ ያልሆነ ወላጅ	1	2	3	4	5
323	ከልጄ ከአሁኑ በላይ የቀረበና የጠነከረ የስሜት ትስስር እንደሚኖረኝ እገምት ነበር፣ አሁን አለመኖሩም ያሳስበኛል	1	2	3	4	5
324	አንዳንዴ ልጄ ሆነ ብሎ የሚያሳስቡኝን ነገሮች ያደርጋል	1	2	3	4	5
325	ልጄ ከአብዛኞቹ ልጆች የበለጠ የሚያለቅስ ይመስለኛል	1	2	3	4	5

ተ/ቁ.	ዝርዝር	በጣም አልስማማም	አልስማማም	አርግጦኝ አይደለሁም	እስማማለሁ	በጣም እስማማለሁ
326	በአጠቃላይ ልጄ በመጥፎ ስሜት ሆኖ ከእንቅልፉ ይነቃል	1	2	3	4	5
327	ልጄ በጣም ስሜታዊ እና በትንሹ ተናዳጅ እንደሆነ ይሰማኛል	1	2	3	4	5
328	ልጄ እጅግ በጣም የሚያሳስቡኝን የተወሰኑ ነገሮች ያደርጋል	1	2	3	4	5
329	ልጄ የሆነ የማይወደው ነገር ሲከሰት አምርሮ ምላሽ ይሰጣል	1	2	3	4	5
330	ልጄ በጥቃቅን ነገሮች በቀላሉ ይበሳጫል	1	2	3	4	5
331	የልጄን ምግብና መኝታ ሰዓት ለማስለመድ ከጠበቅሁት በላይ ከባድ ነበር	1	2	3	4	5
332	ልጄ አንዳች ነገር እንዲሰራ ወይም መስራት እንዲያቆም በምፈልግበት ወቅት የሚከተሉትን ነገሮች ተረድቻለሁ 1. ከጠበኩት በላይ በጣም ከባድ ነው 2. በመጠኑም ቢሆን ከጠበኩት በላይ ከባድ 3. እንደጠበኩት ከባድ ነው 4. በመጠኑም ቢሆን ከጠበቅኩት ይልቅ ቀላል ነው 5. ከጠበኩት ይልቅ በጣም ቀላል ነው	1	2	3	4	5
333	በጥንቃቄ ያስቡና ልጅዎ ከሚያደርገው ነገሮች የሚያሳስብዎትን ይቁጠሩ። (ለምሳሌ፡ አለማዳመጥ፣ ማልቀስ፣ ጣልቃ መግብት፣ መደባደብ፣ መንቀሻቀሻ፣ መጫወት፣ መንቀረፋፋ፣...) ለራስዎ የቆጠሯቸውን ነገሮች ብዛት ያካተተውን ምርጫ ይምረጡ 1. 1-3 2. 4-5 3. 6-7 4. 8-9 5. 10+	1	2	3	4	5
334	ልጄ የሚያደርጋቸው፣ በጣም የሚያሳስቡኝ አንዳንድ ነገሮች አሉ	1	2	3	4	5
335	ልጄ ከጠበቅሁት በላይ ችግር ሆኖብኛል	1	2	3	4	5
336	ልጄ ከአብዛኞቹ ልጆች በበለጠ ከእኔ የሚፈልጋቸው ነገሮች በዙ ፍቸው	1	2	3	4	5

ክፍል አራት፡ የቤተሰብ መድሎ/መገለል መጠይቅ ሰንጠረዥ (Stigma Scale)

ተ/ቁ.	ዝርዝር	ፈጽሞ (0)	አንዳንድ (1)	አልፎ አልፎ (2)	ብዙ ጊዜ (3)
401	በተለየ ሁኔታ እንክብካቤ ሲደረግልዎ መጨነቅ	0	1	2	3
402	ችግሩን ሌሎች ሰዎች ሊያውቁት እንደሚችሉ በማሰብ መጨነቅ	0	1	2	3
403	ይህን ችግር ከሌሎች ለመደበቅ አስባለሁ (ልጅዎ ችግር እንዳለበት ለመግለጽ አይፈልጉም)	0	1	2	3
404	ሌሎች ሰዎች ስለ ኦቲዝም እንዲያውቁ/እዲረዱ ይጥራሉ	0	1	2	3
405	ይህንን ችግር እንደሚስጥር ይዘው ለመቆየት ሞክረዋል	0	1	2	3

406	ስለ መገለል ይጨነቃሉ	0	1	2	3
407	በሰዎች አእምሮ እንዳለው የእብድ ሥእል አይነት ስላለመሆናቸው አስረዳለሁ/ግንዛቤ እሰጣለሁ	0	1	2	3
408	ሰዎች የእኔ ችግር አድርገው እንደሚወቅሱኝ አስባለሁ	0	1	2	3
409	ሰዎች በጋብቻ ከቤተሰቤ ጋር ለመጣመር ፈቃደኛ ላይሆኑ ይችላሉ ብዬ አስባለሁ	0	1	2	3
410	ወደ ውጭ ለመውሰድ ወይም ይዜ ለመሄድ እጨነቃለሁ	0	1	2	3
411	አንገት መድፋት እና ማፈር ይሰማኛል	0	1	2	3
412	ሌሎች ተመሳሳይ ችግር ያለባቸውን ወላጆች አፈላልጌ አገኛለሁ	0	1	2	3
413	በዚህ ምክንያት ሀዘን ወይም ውጥረት ውስጥ እገባለሁ	0	1	2	3
414	በተወሰነ መልኩ ችግሩ በእኔ ምክንያት እንደተከሰተ ይሰማኛል	0	1	2	3

ክፍል አምስት: የቤተሰብ ችግሮች ላይ ያዉጠነጠኑ ግላዊ ምዘና መጠይቅ (Soliyana, 2015).

አላማ:

የዚህ መጠይቅ አላማ: ቤተሰቦች ችግር ሲገጥማቸው መፍትሔ ለማበጀት የሚጠቀሟቸውን ችግር ፈቺ አመለካከቶችንና ባህሪያትን ለመገንዘብ ነው።

መመሪያ:

1. የቀረቡትን የመልስ አማራጮች ያንብቡ።
2. ቀጥለው የተዘረዘሩት አረፍተ-ነገሮች የእርስዎን ችግር ፈቺ አመለካከቶችንና ባህሪያት ምን ያህል እንደሚገልፁ ያመልክቱ።
3. እያንዳንዱ አረፍተ-ነገሮች ላይ ምን ያህል እንደሚስማሙ ወይም እንደማይስማሙ ከሚቀጥሉትን አምስት ምርጫዎች አንዱን መርጠው ያክብቡ።

በቤተሰብ መካከል ችግር/የክብደ ነገር ሲፈጠር፣ ምላሽ የምንሰጠው

ተ/ቁ.	ዝርዝር	በጣም አልስማማም	አልስማማም	አርግጦኛ አይደለሁም	እስማማለሁ	በጣም እስማማለሁ
501	የክብዱንን ነገሮች ለቤተዘመዶች በማካፈል	1	2	3	4	5
502	ማበረታቻና ድጋፍን ከጓደኞች በመፈለግ	1	2	3	4	5
503	ዋና ዋና ችግሮችን ለመፍታት የሚያስችል አቅም እንዳለን በማወቅ	1	2	3	4	5
504	አንድ አይነት/ተመሳሳይ ችግር ከገጠማቸው ሌሎች ቤተሰቦች መረጃና ምክር በመፈለግ	1	2	3	4	5
505	ከቤተዘመዶች ምክር በመጠየቅ (ምሳሌ ከአያቶች፣ አጎች፣ አክስት...)	1	2	3	4	5
506	የኛን አይነት ችግር ለመፍታት ከተቋቋሙ ማህበረሰባዊ ግልጋሎት ሰጪ ተቋማት/ፕሮግራሞች ድጋፍ በመፈለግ	1	2	3	4	5
507	የኛን ችግር መፍታት የሚችል ጥንካሬ በራሳችን ቤተሰብ ውስጥ እንዳለ በማወቅ	1	2	3	4	5
508	ስጦታና ውለታ ከጎረቤቶቻችን በመቀበል (ምሳሌ፡- በምግብ፣ በመላለክ)	1	2	3	4	5
509	ከቤተሰብ ሀኪም መረጃና ምክር በመፈለግ	1	2	3	4	5
510	ከጎረቤቶቻችን ውለታና እገዛን በመጠየቅ	1	2	3	4	5
511	ችግሮችን በመጋፈጥና አፋጣኝ መፍትሔዎችን ለማግኘት በመሞከር	1	2	3	4	5
512	ቴሌቭዥን በመመልከት	1	2	3	4	5
513	ጠንካራ (ብርቱ) መሆናችንን በማሳየት	1	2	3	4	5
514	የሀይማኖት ፕሮግራሞችን በመካፈል	1	2	3	4	5
515	አስጨናቂ ክስተቶች (ሁኔታዎችን) እንደ አይቀሬ የሀይወት እውነታ በመቀበል	1	2	3	4	5
516	ስጋቶቻችንን ለቅርብ ጓደኛ በማካፈል	1	2	3	4	5
517	እድል የቤተሰባችንን ችግሮች በምን ያህል ጥራት መፍታት የምንችልበትን ትልቅ ሚና እንደሚጫወት በማወቅ	1	2	3	4	5
518	ከጓደኞች ጋር እስፖርት እየሰራሁ ራስን መጠበቅና ጭንቀትን በመቀነስ	1	2	3	4	5
519	ችግሮች ሳይጠበቁ እንዲሟከሱ በመቀበል	1	2	3	4	5
520	ከቤተዘመድ ጋር የጋራ ቆይታ በማድረግ (ምሳሌ፡- በመሰባሰብ አንድ ላይ መብላት)	1	2	3	4	5
521	ለቤተሰባዊ ችግሮች የባለሙያ ምክርና እርዳታን በመፈለግ	1	2	3	4	5
522	ችግሮቻችንን መሸከም እንደምንችል በማመን	1	2	3	4	5
523	በሀይማኖታዊ ተግባራት በመሳተፍ	1	2	3	4	5
524	የሚያጋጥሙንን የቤተሰብ ችግሮች በበጎ በመተርጎም፣ በራሳችን ወደ አለመተማመን እንዳንገባ በማድረግ	1	2	3	4	5
525	ዘመዶቻችን እኛ ስለገጠመን ችግር ምን እንደሚሰማቸው በመጠየቅ	1	2	3	4	5
526	የቴንም ያህል ዝግጁ ብንሆን ችግሮችን ለመሸከም ሊያስችግረን እንደሚችል በማሰብ	1	2	3	4	5
527	ከሀይማኖት አገልጋይ ምክር በመጠየቅ	1	2	3	4	5
528	አስፈላጊውን ያህል ጊዜ ብንጠብቅ ችግሩ ሊወገድ እንደሚችል በማመን	1	2	3	4	5
529	ችግሮቻችንን ከጎረቤቶች ጋር በመካፈል	1	2	3	4	5
530	በፈጣሪ በመታመን	1	2	3	4	5

ክፍል ስድስት፡ ከቤተሰብ የሚገኝ እርዳታ መለኪያ (Soliyana, 2015).

ከዚህ በታች የተዘረዘሩት ሰዎች/አካላት ብዙውን ጊዜ በቤተሰብ ውስጥ ልጅን ለማሳደግ የሚረዱ ናቸው። ይህ መጠይቅ እያንዳንዱ አካል የአርስዎን ቤተሰብ ምን ያህል እንደሚረዳ እንዲያመለክቱ ይጠይቃል። እያንዳንዱ ሰው/አካል ባለፉት 3 እና 6 ወራት መካከል ቤተሰብዎን ምን ያህል እንደረዳ ከተሰጡት ምርጫዎች ውስጥ ይበልጥ የሚገልፀውን ያክብቡ። በተጠቀሰው የጊዜ ገደብ ውስጥ ከተዘረዘሩት ሰዎች/አካላት በቤተሰብዎ ያልነበረ ቢኖር 'የለም' የሚለውን አማራጭ ያክብቡ። ያልተጠቀሱ ሰዎች ወይም አካላት ካሉ በሰንጠረዥ መጨረሻ ባለው ክፍት ቦታ ውስጥ ይግለጹ።

እያንዳንዱ የተጠቀሱት ሰዎች ልጅዎን በማሳደግ ረገድ ምን ያህል ረድቶዎታል?

ተ/ቁ.		የለም	ምንም አይረዱኝም	አንዳንዴ ይረዱኛል	በአጠቃላይ ይረዱኛል	በጣም ይረዱኛል	እጅግ በጣም ይረዱኛል
601	ወላጆቼ	የለም	1	2	3	4	5
602	የባለቤቴ ወላጆች	የለም	1	2	3	4	5
603	የስጋ ዘመዶቼ	የለም	1	2	3	4	5
604	የባለቤቴ የስጋ ዘመዶች	የለም	1	2	3	4	5
605	ባለቤቴ	የለም	1	2	3	4	5
606	ጓደኞቼ	የለም	1	2	3	4	5
607	የባለቤቴ ጓደኞች	የለም	1	2	3	4	5
608	ትልቁ ልጄ/ልጆቼ	የለም	1	2	3	4	5
609	ጎረቤቶቼ	የለም	1	2	3	4	5
610	ሌሎች ወላጆች	የለም	1	2	3	4	5
611	የስራ ባልደረቦቼ	የለም	1	2	3	4	5
612	የወላጅ ቡድን አባላት	የለም	1	2	3	4	5
613	የማህበረሰብ ቡድኖች	የለም	1	2	3	4	5
614	የእምነት ተቋም አባላት/ሰባኪዎች	የለም	1	2	3	4	5
615	የቤተሰቤ/የልጄ ሀኪም	የለም	1	2	3	4	5
616	በኦቲዝም ማእከል የሚሰጥ ክትትል	የለም	1	2	3	4	5
617	ትምህርት ቤት ወይም አፀደ-ህፃናት	የለም	1	2	3	4	5
618	የሠለጠነ ባለሙያ (ማህበራዊ ሠራተኛ፣ አስተማሪዎች፣ ቴራፒስት)	የለም	1	2	3	4	5
619	ድጋፍ ሰጪ ተቋማት (በማህበረሰብ ጤና፣ በማህበራዊ አገልግሎት፣ በአዕምሮ ጤና ተቋማት)	የለም	1	2	3	4	5
620	_____	የለም	1	2	3	4	5
621	_____	የለም	1	2	3	4	5

ለተሳትፎዎ አመሰግናለሁ!

Appendix-I: A snapshot of how Themes were organized in the Literature Review (Sample)

Author(s), Year and Country	Methods of Data Collection	Sample Size	Central Themes	Major Findings	Topics
Parent Experiences in relation to the Diagnostic Process and Beliefs about Etiology of ASD					
Anthony (2009); Ghana	Focus groups, semi-structured interviews, and text analysis	Nine caregivers of children with autism	Supernatural Reasons Lack of trained medical professionals	Symptoms are a result of magic and transgressions/wrongdoings by the mother. Difficulty of accessing information or professionals to diagnose the disorder.	Etiology Diagnostic Process
Bayat (2007); United States	Survey (Likert-scale) and open-ended questions	175 parents and primary caregivers of children with autism	Conflict to Acceptance	Parents reported initially experiencing depression which eventually turned to love, adjustment, and advocacy	Feelings about Diagnosis
Bilgin & Kucuk (2010); Turkey	Informal interviews	43 mothers of children with autism ranging in age from 6 to 17 years	Unpleasant Emotions	Most parents reported grief, shock, pessimism, denial, and breakdown.	Reactions to Diagnosis
Chamak, Bonniau, Oudaya, & Ehrenberg (2011); France	Questionnaire and in-depth interviews	248 parents were surveyed, and 43 were interviewed. Parents of individuals living with ASD that ranged in age from 4 to 45 years old	Unpleasant Emotions Relief	Parents reported negative reactions to receiving the diagnosis including distress, helplessness, despair, guilt, depression, dejection. Other parents reported feeling relief, understanding, confirmation of what they already knew, and understanding the child's difficulties	Feelings about Diagnosis
Fisseha (2012); Ethiopia	In-depth interview	Six mothers of children with ASD	Mothers' Reactions	Being shocked, crying, anger, disappointment, and a feeling of loss of the child	Reactions to the Diagnosis
McCabe (2008); China	Open-ended questionnaires and semi-structured	78 parents of children with autism ranging in age from 3 to 12 years old	Unpleasant Emotions Lack of Information	Parents reported feeling shocked and overwhelmed after their child's diagnosis. Parents also reported being provided with a lack of information.	Feelings about Diagnosis Diagnostic

	interviews		Conflict to Acceptance	Most parents reported that although their relationships involved more conflict at first, it has evolved into a more collaborative and positive relationship.	Process Feelings about Diagnosis
Meron (2006); Ethiopia	Both interview and questionnaire	40 families of children with autism	Reactions	Feelings of confusion, shock, and self-blame	Reactions upon Diagnosis
Myers, Mackintosh & Goin-Kochel (2009); US	Online survey and open-ended questions	493 parents of children with ASDs	Conflict to Acceptance	Parents reported initially feeling grief, depression, guilt, and blame which later turned to compassion and tolerance	Feelings about Diagnosis
Osborne, McHugh, Saunders, & Reed (2008); UK	15 Focus Group Discussions	70 parents of children ranging from 3 to 18 years old	Lack of Information	Most parents report receiving very little support, advice, or information following the diagnosis	Diagnostic Process
Probst (1998); Cross-cultural Comparisons: Germany, Brazil, Greece, and Italy	Questionnaire and interviews	163 families of primary school-aged children with autism	Specific Cause	All countries with the exception of Greece pointed to biological reasons for their child's symptomology.	Etiology
			Supernatural Reasons	In Greece, most parents reported psychosocial, external reasons for their child's symptoms including that they were "Given by God" or "Fate, Destiny" one parent believing her child's symptoms were due to "bad mental conditions during pregnancy."	Etiology
			Unpleasant Emotions/ Relief	Mixed feelings of either hope or hopelessness/fear for the child with most expressing fear for the future.	Feelings about Diagnosis
Russell & Norwich (2012); United Kingdom	Semi-structured interviews	17 parents of children with ASD ranging in age from 7 to 16 years	Relief	Parents reported being excited about the benefits of the diagnosis including coming to terms with their child's behavior and allowing them to better	Feelings about Diagnosis

		old	Specific Cause	understand it. Most parents believed their child's symptom was the result of biological factors	Beliefs about Etiology
Samadi, McConkey, & Kelly (2012); Iran	Structured interviews	43 parents of children with ASD ranging in age from 3 to 7 years old with an average age of 8.2 years	Multiple Factors Unpleasant Emotions	Parents reported maternal factors (37%), environmental factors (23%), body or brain defect (16%), supernatural reasons (12%), and genetics (7%) were claimed for their child's symptoms. Most parents reported experiencing shock, rejection, depression, uncertainty after receiving their child's diagnosis.	Beliefs about Etiology Feelings about Diagnosis
Shaked & Bilu (2006); Ultraorthodox Jews, Israel	Open-ended interviews	Thirty families (27 mothers, 2 couples, 1 father) of children with ASD	Conflict to Indifference Multiple Factors Supernatural Reasons	The diagnostic journey was an arduous process initially filled with hope, but upon receiving a diagnosis resulting in indifference. Most report medical causes, with around half pointing to psychological conceptualizations of etiology primarily centering on parental self-deprecation. Nearly all of the mothers conveyed their belief that their child's diagnosis was God's will and a form of suffering that the family had been chosen for.	Reaction to Diagnosis Etiology Etiology
Shyu, Tsai and Tsai (2010); Taiwan	Semi-structured interviews	13 parents of children with autism ranging in age from 3 to 7 years old	Specific Cause/Etiology Supernatural Reasons	100% of parents pointed to biological reasons for their child's symptomology. 85% also believed that their child's symptoms were at least in part due to supernatural reasons	Beliefs about Etiology

Author(s), Year and Country	Methods of Data Collection	Sample Size	Central Themes	Major Findings	Topics
Challenges of Parents of a Child Diagnosed with an ASD					
Anthony (2009); Ghana	Focus groups, semi-structured interviews, and text analysis	Nine caregivers of children with autism	Culture Specific Stressor	Families report feeling isolated and stigmatized, unable to attend church, celebrations, or community events with their child.	Emotional Impact
Bayat (2007); United States	Survey (Likert-scale questionnaire) and open-ended questions	175 parents and primary caregivers of children with autism	Significant Stressors Career Interference	Parents reported significant challenges including behavior problems, financial stressors, and fights with the system to get support. Parents reported holding their careers or switching to a career in special needs.	Emotional Impact Career Impact
Bilgin & Kucuk (2010); Turkey	Informal interviews	43 mothers of children with autism ranging in age from 6 to 17 years old (avg age of 9 years)	Significant Stressors	Mothers also reported a lack of acceptance into the community, lack of knowledge, and financial strain.	Challenges
Efrem (2005); Ethiopia	Semi-structured interview	Six parents of children with autism	Challenges	Lack of knowledge about autism, how to handle the situation of these children, and lack of regular schedule to communicate with professionals or therapists).	Challenges
Farrugia (2009); Australia	Semi-structured interviews	16 parents of youth with ASD ranging in age from 5 to 23 years old	Significant Stressors	Parents reported stressors including isolation, having to have their lives very structured, difficulties with school understanding the child's behaviors, and contradicting recommendations.	Emotional Impact
Meron (2006); Ethiopia	Both interview guide and questionnaire	40 families of children with autism	Impact of autism	Challenges of managing the behavior of the children with ASD and how to work effectively with autistic children. Feelings of shame, hopelessness, and having difficulty participating in social activities.	Impacts of Autism on the families

Myers, Mackintosh, & Goin-Kochel (2009); United States	Online survey and open-ended questions	493 parents of children with ASDs	Significant Stressors	70% of parents reported feeling stressed, noting difficulties related to marital strain, school struggles, challenging behaviors, isolation, and disrupted family life.	Emotional Impact
			Career Interference	Parents also reported negative impacts on their careers.	Career Impact
Shaked & Bilu (2006); Ultraorthodox Jews, Israel	Open-ended interviews	30 families of children with ASD	Culture specific Stressor	Families were typically forced outside of the community in an effort to obtain these treatments for their children with many families reporting feeling a great deal of emotional conflict.	Emotional Impact
Shyu, Tsai and Tsai (2010); Taiwan	Semi-structured interviews	13 parents of children with autism ranging in age from 3 to 7 years old	Significant Stressors	Parents reported significant stressors including financial strain, depression, exhaustion, worry, loss of confidence in their parenting abilities, or guilt.	Emotional Impact

Author(s), Year and Country	Methods of Data Collection	Sample Size	Central Themes	Major Findings	Topics
Coping Mechanisms of Parents of a Child with Autism					
Gray, (1994); Australia	Interviews	33 parents of children with ASD ranging in age from 6 to 12 years old	Coping Strategies	- Use of treatment services - Family support - Religion - Social withdrawal	Coping with Autism
Gray (2003); Australia	Semi-Structured Interviews	33 parents of children with ASD	Coping Method	- Planning appropriate responses - Working with their child as a participant in their therapeutic regimen - Talking to friends and family - Spousal support - Religion-based coping	Coping Mechanisms

Hastings & Johnson (2001); United Kingdom	Questionnaire	141 parents of children with Autism	Family Coping Strategies	- Adaptive coping strategies - Informal social support sources - Beliefs about the efficacy of the interventions	Coping Mechanisms
Luther, Canham, & Cureton (2005); United States	Questionnaire	18 parents of children with ASD ranging in age from 5-13 years old	Coping Strategies	- Spiritual guidance - Parent support groups - Reframing (perception of stressful experience) - Social support - Avoidance	Coping Mechanisms
Marshall & Long (2010); Canada	Open-ended interviews	5 mothers of children with autism (aged 6–11 years)	Coping Methods	- Action-oriented/problem-focused: seeking interventions for the child, changing life circumstances, problem-solving, and sharing knowledge of autism with others - Making meaning/cognitive reappraisal: making sense of challenging situations - Seeking social support: parent support groups and professional support - Spirituality: believing in supernatural powers	Coping Mechanisms
Pottie & Ingram (2008); United States	Questionnaire	93 parents of children with ASD	Coping outcomes	- Adaptive: problem-focused, social support, positive reframing, emotional regulation, and compromise. - Maladaptive: escape, blaming, withdrawal, and helplessness	Coping Mechanisms
Rodrigue, Morgan, & Geffken (1990); United States	Questionnaire	20 mothers of children with an average age of 10.71 years old	Coping Method	- Information seeking - Wish-fulfilling fantasy - Self-blame	Coping Strategies
Sivberg (2002); Sweden	Questionnaire	66 parents of individuals with autism disorder (aged 1–26 years old)	Coping Strategies	- Distancing - Escape - Social support (both emotional & instrumental) - Planning	Coping Mechanisms

Tadesse (2014); Ethiopia	In-depth interview	Six families of children with Autism	Ways of Coping	- Accepting the situation - Changing the meaning of autism to a positive - Blaming God or themselves, and - Avoidance	Coping Mechanisms
Tarakeshwar & Pargament (2001); United States	Semi-structured Interviews	45 parents of children with ASD ranging in age from younger than 4-24 years old	Religious Coping Strategies	- Negative Religious Coping Strategies (God as unhelpful in parenting their child, perception of religious experiences as aversive to the coping process, and feelings of punishment or having doubts about the benevolence of God) - Positive Religious Coping Strategies (being part of God's plan, and an opportunity for spiritual growth)	Religious Coping
Twoy, Connolly, & Novak (2007); United States	F-COPES Questionnaire	55 families of children with autism	Coping Strategies	- Acquisition and acceptance of help from family - Passive appraisal (i.e., avoidance) - Reframing (i.e., positive thinking) - Seeking spiritual support - Acquiring social support	Coping Mechanisms

Author(s), Year and Country	Methods of Data Collection	Sample Size	Central Themes	Major Findings	Topics
Available Supports and Services for Parents of a Child with Autism					
Anthony (2009); Ghana	Focus groups, semi-structured interviews, and text analysis	9 caregivers of children with autism	Lack of Services or Metaphysical services	Lack of access to inclusive education leaving many to attempt treatments from spiritual leaders.	Services
Bilgin & Kucuk (2010); Turkey	Informal interviews	43 mothers of children with autism ranging in age from 6 to 17 years	Support Outlets	Mothers reported their husbands, extended family, and friends as sources of support.	Sources of Support

Bromley, Hare, Davison, & Emerson (2004); United Kingdom	Interviews	68 mothers of children with ASD ranging in age from 5 to 18 years	Support Outlets	Parents reported having support from coworkers, parents' groups, social groups/clubs, religious organizations, and early intervention programs.	Sources of Support
Farrugia (2009); Australia	Semi-structured interviews	16 parents of youth with ASD ranging in age from 5 to 23 years old	Support Outlets	Parents reported feeling new sources of interpersonal connection through support group meetings.	Sources of Support
Helen (2016); Ethiopia	In-depth interview	Six Mothers of children with ASD	Supports	Relied on supports from spouses, family members, and/or organizations.	Social Support
McCabe (2008); China	Open-ended questions and semi-structured interviews	43 parents of children with autism ranging in age from 3 to 11 years old	Support Outlets	Parents expressed important benefits of parent-to-parent support including sharing and learning from one another, support, and feeling of acceptance.	Sources of Support
Osborne, McHugh, Saunders, & Reed (2008); UK	15 Focus Group Discussions	70 parents of children ranging from 3 to 18 years old	Support Outlets	Parents reported they desired greater connection with support groups and more frequent meetings.	Sources of Support
Probst (1998); Comparisons in: Germany, Brazil, Greece, and Italy	Questionnaire and interviews	163 families of primary school-aged children with autism	Various Treatment Attempts	All cultures believed educational and psychological treatments were of great importance.	Treatment Decision-Making
Shaked & Bilu (2006); Ultraorthodox Jews, Israel	Open-ended interviews	30 families of children with ASD	Various Treatment Attempts Metaphysical	Parents reported seeking out a number of medical, educational, and alternative interventions. Parents also reported seeking spiritual and mystical treatments for their children.	Treatment Decision-Making
Shyu, Tsai and Tsai (2010); Taiwan	Semi-structured interviews	13 parents of children with autism ranging in age from 3 to 7 years	Various Treatment Attempts/ Metaphysical	Parents sought several treatments and services including acupuncture, occupational or speech therapy, treatment for food allergies, detoxification therapy, and vitamin supplements.	Services