



Addis Ababa University

College of Education and Behavioral Studies

School of Psychology

Psychological Experience of Parents of Children with Autism at St. Paul Hospital  
Millennium Medical College in Addis Ababa, Ethiopia

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# Psychological Experience of Parents of Children with Autism

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# Psychological Experience of Parents of Children with Autism

## **LIST OF ACRONYMS AND ABBRIVIATIONS**

ASD	Autism Spectrum Disorder
CDC	Center for Disease Control and Prevention
MWCY	Ministry of Women's Children and Youths
MOH	Ministry of Health
PBS	Positive Behavioural Support

# Psychological Experience of Parents of Children with Autism

## Table of Contents

List of table .....	vi
Abstract .....	vii
CHAPTER ONE .....	1
INTRODUCTION .....	1
1.1 Background of the Study.....	1
1.2 Statement of the Problem.....	5
1.3 Research questions .....	8
1.4 Objectives of the study .....	8
1.5 Significance of the Study.....	8
1.6 Definitions of Terms.....	9
1.7 Scope of the study .....	9
CHAPTER TWO .....	10
REVIEW OF RELATED LITERATURE.....	10
2.1. Overall perspective of Autism .....	11
2.1.1 Spectrum Nature of ASD .....	12
2.1.2 Comorbidities in ASD .....	13
2.2. Impact of Autism on Family Dynamics.....	14
2.3. Psychological impacts .....	15
2.4. Coping mechanisms.....	17
2.5 Service availability .....	19
CHAPTER THREE .....	21
METHODOLOGY .....	21
3.1 The Study Design .....	21
3.2 Study area and period .....	21
3.3 Population .....	22
3.4 inclusion and exclusion criteria.....	22
3.5 Sample size and sampling technique .....	22
3.6 Data Collection Topic Guides.....	23
3.7 Data Quality Assurance .....	24
3.8 Method of Data Analysis .....	24

# Psychological Experience of Parents of Children with Autism

3.9 Ethical Considerations .....	24
CHAPTER FOUR .....	25
RESULT .....	25
CHAPTER FIVE.....	36
DISCUSSION.....	36
CHAPTER SIX.....	41
CONCLUSION AND RECOMMENDATION .....	41
6.1 Conclusion .....	41
6.2 Recommendation.....	41
REFERENCES .....	43
ANNEX.....	55
ENGLISH VERSION QUESTIONNER.....	55
AMHARIC VERSION QUESTIONNER (አማርኛው ትርጉም) .....	59

# Psychological Experience of Parents of Children with Autism

## **List of table**

Table 1. Sociodemographic information of Parents of children with Autism

# Psychological Experience of Parents of Children with Autism

## Abstract

*This study is aimed to explore the psychological experience of parents of children with Autism at St Paul Hospital Millennium Medical College. An institutional-based qualitative phenomenological study was conducted through an in-depth interview, using purposive sampling techniques. Nine participants participated in the data collection. Semi structured questionnaire were used for data collection supported by recorders and field notes. Thematic analysis was applied to transcribe code, categorize and develop themes from the data. The finding of this study indicates that these parents frequently encounter considerable psychological difficulties including stress, anxiety, self-isolation, poor self-care, anger and sadness. Both fathers and mothers of children with Autism are affected by the situation. Cultural perceptions and shortage of services further exacerbate these challenges. Despite these difficulties, parents employ coping strategies such as religion, acceptance, resilience, emotion focused coping and Complaint to government officials by letter. Parents also expressed their frustration with the inadequate educational and health care services. Parents suggested that the educational curriculum should be reviewed, and they emphasized the need for training for healthcare professionals. This study signifies the need for improved support systems for parents of children with autism, emphasizing the importance of addressing both their needs and the societal factors that influence their experiences. It is recommended to organize community events, provide adequate educational facilities and health care service. Additionally policy should be developed to improve access to services and protect the rights of individuals with autism and their families.*

**Key words:** *Autism Spectrum Disorder (ASD), parents, psychological experiences, coping strategies and support*

# CHAPTER ONE

## INTRODUCTION

### 1.1 Background of the Study

Parenting is a universal experiences which is a complex emotional journey marked by both joy and challenges. Parents often find profound fulfillment in witnessing their children's milestones, such as first steps or achievements in school, which instill a sense of pride and joy (Friedman & Heller, 2007). Each developmental stage presents unique challenges; for instance, the transition from toddlerhood to adolescence requires parents to adapt their strategies and expectations continuously (Lunsky & Neely-Barnes, 2010). Managing responsibilities between work, household duties, and parenting can lead to feelings of being overwhelmed (Schultz & Schmidt, 2016).

Parents who are raising a child with a disability may not only managing day-to-day caregiving but also advocating for their child within medical, educational, and social systems (Schneider, 2019). According to Lloyd and Houghton(2018) the initial response to learning that one's child has a disability can range from shock and disbelief to deep emotional turmoil. Parents may experience a range of emotions including grief, guilt, and fear as they come to terms with the diagnosis.

As Dunlap et al. (2020), highlight children with disabilities may face barriers in their educational settings, social circles, and even within their own families. These challenges may impact their social development, self-esteem, and overall mental health, but they can also lead to a profound sense of resilience as they navigate these obstacles. Children with disabilities often require tailored interventions, including therapies, educational modifications, and sometimes medical treatments, to thrive (Kauffman & Hallahan, 2017). As parents become more attuned to their child's needs, they gain deeper insights into the child's abilities and the potential for overcoming challenges (Hughes & Lynch, 2019).

Among different disabilities, Autism spectrum disorder (ASD) is group of conditions due to impairment in physical, learning, language, or behavior areas that can cause significant social,

# Psychological Experience of Parents of Children with Autism

communication and behavioral challenges. People with ASD may communicate, interact, behave, and learn in ways that are different from most other people; and, their learning, thinking, and problem-solving abilities can range from gifted to be severely challenged. ASD occurs in all racial, ethnic, and socioeconomic groups (Maenner, 2023).

ASD is a neurological and developmental disorder that usually appears during the first three consecutive years of a child's life (Willis, 2007). It has multiple characteristics that affect children and their parents including Communication impairment, social interaction, emotional functioning, engagement in repetitive activities, and stereotyped movements are some characteristics associated with autism (Willis, 2007).

Studies through the world showed an increasing trend in magnitude of ASD. Besides the true increase in the prevalence of ASD, this might be due to a broader definition of ASD, changes in diagnostic criteria and screening tools, shifts in research methods, and increased awareness of ASD, have been suggested to contribute to this phenomenon (Durkin et al., 2017).

Studies also showed the magnitude of ASD being of four to five times more in boys than girls. The average prevalence of autism spectrum disorder in Asia, Europe and North America is estimated at 1% (Chiarott, 2020). According to the US Centers for Disease Control and Prevention (CDC) 2018 report, the magnitude of ASD among children aged 8-year-old was 1 in 59 in 2014 and 1 in 54 in 2016 (Maenner, 2021). The prevalence of ASD in children and adolescents in the United States was reported at 2.5% in 2014–2016 (Xu et al., 2018).

In another study in Italy, the prevalence of ASD among 7–9-year-old children was 1.15% (Narzisi et al., 2020). In Asia, the prevalence of ASD has been reported to be 3.9%, with a prevalence of 0.14 to 2.9% in the Arab countries around the Persian Gulf (Qiu, 2020; Alshaigi et al., 2020). It is important to obtain an accurate estimation of the prevalence of autism to determine the economic burden and health services and allocate sufficient budget and services to autistic children or adults and their families (Boswell et al., 2014). In addition, by accurately determining the prevalence of ASD, vulnerable groups and geographical and environmental risk factors can be identified (Imm et al., 2019)

In Africa the prevalence of autism is unknown because of autism research conducted in Africa has been infrequent and unrepresentative of all African nation (Bakare et al., 2011). The same is

## Psychological Experience of Parents of Children with Autism

true for Ethiopia currently there are no studies made on the prevalence of autism in Ethiopia however according to the estimation made by Gebre(2016), There could be about 530,000 children with autism and related developmental disorder in Ethiopia.

Compared to other developmental deviations such as intellectual impairment, autism manifests itself not in developmental delays but rather in striking deviations in development (Beauchesne& Kelley, 2004). Children diagnosed with an ASD are not the only people being affected by these disorders; their families of these children experience enormous struggles on a daily basis that often go unrecognized. Parenting a child diagnosed with an ASD has been shown to be more stressful than parenting a child with any other disability and mothers of these children are more likely to suffer from depression than the general population (Davis & Carter, 2008).

The challenges of caring children with autism can result in pronounced psychological distress for mothers (Davis & Carter, 2008). There is the acknowledgment of potential loss of self and family image and livelihood, which implies a unique parenting experience with different expectations, hopes and dreams for the child and family to what they had anticipated (Woodgateetal, 2008).

Managing children with ASD requires individualized intensive programs that includes behavioral, educational, and psychological interventions, usually provided in specialized autism centers.(Zablotsky etal.,2015). Once these children are diagnosed with ASD, they should be assessed and managed using these specialized programs. Beginning such multidisciplinary treatment early increases the likelihood of a favorable outcome, however, this is not always possible (Sun Etal, 2013). It is evident that autism centers are under pressure to accept an increasing number of children and required to recruit specially trained personnel to educate and effectively modify challenging behaviors.

Studies in developing countries showed considerable delays in the provision of such services, mostly due to the under-developed service systems. (Vohraetal , 2014). On the other hand, caregivers of children with ASD often report difficulties in using available services, inadequate financial coverage, and lack of shared decision making and care coordination (Al-Farsi et al., 2013). Readily available autism services are of paramount importance in order to provide adequate rehabilitation of affected children and their families, and improve their quality of life

## Psychological Experience of Parents of Children with Autism

(Amr et al., 2012). Studies showed parents of children with autism are left with the most demanding challenges that require them to decide on the type of therapies that are appropriate to their children. This challenge might be more problematic, especially in the absence of well-established consensus regarding appropriate educational practices (Dunlap et al., 2008).

Study showed that families of children with ASD have dissatisfied with the quality of autism services (Chiri & Warfield, 2012). A study in the USA revealed that these parents demanded high-quality autism services. For example, they requested for nationally and easily accessible autism services (Dymond et al., 2007). Furthermore the study which is conducted in USA by using national data, stated that families face barriers in obtaining intervention for their children, and their children are at risk of having unmet care needs (Chiri & Warfield, 2012).

Studies showed that that social support, peer support and hope are strategies that help alleviate distress among families of children with ASD. These strategies have the potential to help them cope with the needs of children with ASD because they favour emotional support and information exchange, promote family well-being, contribute to strengthening family functioning, and relieved anxiety and stress. They also provide an optimistic perspective of the future in coping with the condition and in adapting in periods of crisis (Brown et al., 2009). On the other hand Hartley and Schultz (2015), reported that parents value support for family-wide impacts, developing partnerships with professionals, becoming educated on ASD, obtaining individualized education plans, and parent self-care.

A study conducted in Ethiopia reported that like other African countries has limited autism service provision. In Ethiopia services for children with autism and their families are centralized in the capital city. There are four types of service providers: 1) two psychiatric clinics in government-run hospitals and a private clinic, 2) two centers run by parents of children with autism, 3) one government and two private schools which have inclusive education programs for children with autism and 4) two community-based organizations (Tekola et al., 2016). The scope of Ethiopian service providers tends to be broader than typically seen in high-income countries, with the parent-run centers and community-based organizations also providing some informal diagnoses. Access to centers run by parents of children with autism is mostly restricted to well-educated and more affluent families; these centers also have long waiting lists. There are no

# Psychological Experience of Parents of Children with Autism

diagnostic or educational services in the rural areas, where 85% of the population lives. This makes autism usually remains undetected.

## **1.2 Statement of the Problem**

Studies suggested that children with ASD have deficits in social interactions, in verbal and nonverbal social communication skills, as well as intelligence and motor functions. These children also exhibit unusual interests, repetitive behaviors, and unusual responses to sensory experiences (Lord, 2018). Autism spectrum disorder is associated with high levels of anxiety, stress, and isolation in families (Bozkurt et al., 2019; Cohrs&etal., 2017).

ASD is a lifelong neurodevelopmental disorder that currently has no cure, and its presence in a family may affect the whole aspects of the family's life in all stages of the family cycle particularly from family expansion through completion of expansion and it makes family contraction difficult. Parenting a child with autism disorder(s) is likely to be more stressful and overwhelming for the parents or caregivers particularly who live in the resource-poor country like Ethiopia. Lack of access to the needed resources and support services may prevent the parents from meeting the family's life demands and contribute to the family disorganization. Possible internal and external factors associated with raising an ASD child may adversely affect the family's life-style by weakening the family's strength and influencing the parents 'perception of own self-efficacy. (Leigh &Du , 2015).

According to Sander and Morgan(1997), Autism have impact on most aspects of parents lives, including housekeeping, finances, the emotional and mental health of parents, marital relationships, physical health of family members, limiting the response to the needs of other children within the family, poor sibling relationships, relationships with extended family, friends and neighbors, the opportunities for the personal development of each family member and time spent in family recreation and leisure activities (Sander & Morgan, 1997).

Raising a child with an autism spectrum disorder (ASD) is an overwhelming experience for parents and families. This might be due to decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. In addition to

## Psychological Experience of Parents of Children with Autism

significant financial strain and time pressures, studies showed high rates of divorce and lower overall family well-being among parents with ASD child (Karst&VanHecke, 2012).

Raising a child with autism comes with a lot of challenges, which significantly impacts parental stress (Karst & Van Hecke,2012). Parents of children with ASD experience significantly more stress than parents of children without disabilities, but also of parents whose children have other developmental disabilities (Samadi et al ., 2012).Similarly another study also showed that parents having autistic child had more stress and emotional disturbance which leads to conflict, divorce and family crises (Demissie,2015).

According to Sid and Kumar (2022) most parents with ASD child use Emotion Focused Coping Strategies which includes sleeping, crying, Visiting Spiritual Places and Attempting Suicide. The study also detailed mothers preferred to sleep to pass the moment when sometimes things get out of control due to the child's behavior making sure that her child is also sleeping beside her, believed that crying for a while gave them a relief from stress.They also suggested other coping, mechanism such as corporal punishment and chaining the child with ASD, overlooking the child's action and retreating and problem-focused coping strategies. Of the above mechanisms corporal punishment and chaining the child with ASD was practiced by fewer parents.

Now, there are services for parents and children with ASD that is covered under insurance for qualifying individuals with ASD, however even with these services for the child with autism, daily life still remains stressful for some parents with children with ASD (Nealy et al., 2012). A child can be as young as 18 months to obtain an initial diagnosis of ASD to begin receiving these services (Murray et al., 2016). Currently, there are few services for parents. The current services that exist today do help the individual with ASD, which in turn helps the parents, however more programs and Identifying Supports for parents of children with ASD services for parents need to be available (Hartley & Schultz, 2014). Thus, parents of children with autism experienced some psychological problems which are related to social and economic shortages while rising and supporting their children (Papadopoulos et al., 2019).

Studies suggested that psychosocial interventions which are interpersonal or informational activities, techniques, or strategies that aim to improve the health, functioning and wellbeing of children by targeting biological, behavioral, cognitive, emotional, social, or environmental

# Psychological Experience of Parents of Children with Autism

factors that affect autism outcomes should be offered to parents of child with ASD that might include offer to help with things like babysitting, meals or emotional support (Bozkurt et al., 2019; Cohrs<sup>ê</sup>tal., 2017).

Regarding service for parents a study among 102 participants comprised caregivers of children with developmental disorders attending two child mental health clinics in Addis Ababa reported that the majority (75%) of caregivers reported unmet needs regarding their child's educational provision and many (47%) also indicated an unmet need for support from health professionals. (Tilahun et al., 2016) Another study in Ethiopia showed that children with autism spectrum disorders (ASDs) who were enrolled in intervention underserved due to a dearth of available professionals, low number of training facilities, and inadequate resources for family support (Zelege et al., 2018). Many studies have been conducted on autism and its symptoms or characteristics by different researchers and academics.

Children with Autism not the only ones affected by the condition, their parents also significantly influenced. Parents of children with autism encounter different psychological experiences and may varied thorough child's different developmental stages.

Many studies have explored the impact of autism on children, but there is a significant gap in research examining the lived experiences of parents. Most of the existing studies focus primarily on the lived experiences of mothers. In Ethiopia, there has been limited research conducted on this topic.

This study focuses on the psychological experiences of parents (both mothers and fathers) raising children with autism, aiming to understand their feelings, beliefs, and perspectives. Through examining these experiences, this research seeks to explain how supports and interventions that could boost the overall well-being of these families. Additionally, the psychological challenges that affect their mental well-being may improve if these parents receive the necessary support and services.

Having an insight about the psychological experiences of parents of children with autism is important for developing effective support systems. This study contributes to fill the existing gap in the literature, offering valuable insights that can guide future practices and policies aimed at supporting families of children with autism.

# Psychological Experience of Parents of Children with Autism

## 1.3 Research questions

The present study tried to answer the following research questions.

- ❖ What diverse psychological experience parents of children with autism encounter?
- ❖ What strategies do parents of children with autism to address the difficulties linked to autism?
- ❖ What type of supports do parents of children with autism require?

## 1.4 Objectives of the study

### 1.4.1 General Objective

The general objective of this study is to assess the psychological experience of parents of children with autism, coping mechanisms and need of support in the case of St Paul hospital millennium medical college in Addis Ababa Ethiopia 2024.

### 1.4.2 Specific Objectives

- To assess the psychological experiences of parents of children with autism, in Addis Ababa Ethiopia.
- To identify strategies parents of children with autism are using to deal with the challenges when raising a child with autism in Addis Ababa Ethiopia.
- To identify the type of supports do parents of children with autism require, in Addis Ababa Ethiopia.

## 1.5 Significance of the Study

The study will provide evidence for those who are willing to undertake a similar study on the case and promote future studies that are concerned with the stated problem. The results of this study will also be influential input for counselors, planners, and policymakers including the Ministry of Women's Children and Youths (MWCY) and Ministry of Health (MH). Institutions working on autism care and treatment can be benefited from this study as an input for the enhancement of their programs.

# Psychological Experience of Parents of Children with Autism

## 1.6 Definitions of Terms

The following text will be defined to enhance the knowledge of the readers and to provide them with a better understanding of autism.

- ✓ **Autism:** is a developmental disorder, present from early childhood that can affect how people understand, see, hear, and sense the world around them. It is characterized by impairment in social interaction, impairment in communication, and restricted, repetitive and stereotypic patterns of behavior, interests, and activities.
- ✓ **Psychological experiences:** many parents of children with autism experience the following mental states such as: Feelings overwhelmed, grief, depression, anxiety, sadness, anger at their spouse, despair at the incurable nature of the disorder, feelings of social isolation, embarrassment at their child's behavior in public, social stigma, and discrimination.
- ✓ **Psychological support:** parents of children with autism need encouragement, and training/intervention how to live with autistic child.
- ✓ **Parent:** a mother or father of a person, or someone who looks after a person in the same way that a parent does.
- ✓ **Child:** is a person of either sex who has not attained the full age of eighteen years. For this study purpose, the researcher focused on parents of these children.
- ✓ **Support:** services, resources, professional assistance include emotional support and counseling, educational resources, and community programs.

## 1.7 Scope of the study

The current study aimed at assessing the psychological experiences of parents of autistic children at St Paul hospital millennium medical college. The study is delimited, to parents of autistic children who are regularly coming to the hospital in matters related to their children and themselves and interested parents to participate in this study.

# Psychological Experience of Parents of Children with Autism

## CHAPTER TWO

### REVIEW OF RELATED LITERATURE

Autism spectrum disorder (ASD) is a condition with many different features that has been studied a lot in recent years. Many studies have explored its spectrum nature, symptoms, diagnosis, treatment options, and the broader impact on individuals, and society. Baron-Cohen (2020) emphasizes, *“Our understanding of autism has expanded significantly over the years. It is crucial to recognize the spectrum nature of the condition to provide better support for individuals and families.”*

Children with autism have their own character, skills, preference and struggle. Every child who is diagnosed with ASD has different spectrum nature which means children with ASD may exhibit a wide range of skills, challenges, and characteristics. Children with high functioning autism may excel in specific areas, such as mathematics, music, or art and showing impressive talents, while children with low functioning autism may struggle with basic everyday tasks, requiring additional support. Some children with ASD may have struggle in communication abilities they may use nonverbal and alternative methods to express themselves, while others may speak fluently but find it challenging to interpret social cues, such as body language or tone of voice. In social interaction some of them may actively seek friendships with peers and social engagement, while others may feel overwhelmed in social settings may lead to discomfort. Most of them struggle with sensory sensitivities issues; being either hypersensitive or hyposensitive to sounds, lights, textures, or tastes. Some of them may engage in repetitive behaviors or maintain strict routines, while others may display more flexibility in their activities.

As many studies suggests that those challenges which are faced by children with autism are varied and can range from mild to severe, which need vary levels of support for daily living, communication, and social skills. Having knowledge about spectrum nature of autism is essential for providing effective and personalized interventions that address the unique needs of each person, promoting their well-being and supporting their success in their communities.

# Psychological Experience of Parents of Children with Autism

## 2.1. Overall perspective of Autism

The term "autism" derived from the Greek word "autos" meaning "self," was first introduced Swiss psychiatrist Eugene Bleuler in 1911 to describe symptoms associated with schizophrenia, particularly social withdrawal (Bleuler, 1950). Later an Austrian-American psychiatrist Leo Kanner, who published a seminal paper in 1943, introducing the term "early infantile autism." Kanner identified a consistent pattern of behaviors in 11 children, including social engagement deficits and communication difficulties (Kanner, 1943). During the same time, Hans Asperger studied children with similar traits but higher cognitive abilities, publishing his findings in 1944 under the term "autistic psychopathy," which would later become known as Asperger syndrome (Asperger, 1944).

In 1980, the DSM-III included autism as a distinct diagnosis, standardizing diagnostic criteria and distinguishing it from other developmental disorders (American Psychiatric Association, 1980). The DSM-IV in 1994 expanded the definition, introducing subtypes such as Asperger syndrome and pervasive developmental disorder-not otherwise specified (PDD-NOS) (American Psychiatric Association, 1994). In 2013, the DSM-V further refined the criteria, consolidating autism and related disorders under the term "Autism Spectrum Disorder" (ASD), emphasizing the continuum of severity and support needs (American Psychiatric Association, 2013).

Autism spectrum disorders (ASD) is a group of neurodevelopmental conditions that are defined by impairment in three areas: social interaction, communication or use of verbal and non-verbal language, and a stereotyped, restricted or repetitive pattern of behavior, interest and activities (American Psychiatric Association, 2013). According to Orlensky (1988) there are generally three main characteristics used to determine an autism spectrum disorder (ASD), these characteristics are deficits in social interaction, verbal and nonverbal communication, and repetitive behaviors and interests. It is a worldwide problem among all races, nationalities and social class which affects only 4 or 5 every 10,000 persons.

A 2005 report by Mesibov et al. (2005), showed that with a tenfold spike in numbers over the past 20 years-one in every 166 children is now diagnosed with autism and majority of them were boys. Autism can be emotionally devastating for parents, especially just before and after the child is diagnosed. This includes stress of navigating complicated therapy schedules, following

# Psychological Experience of Parents of Children with Autism

through on treatment at home, juggling family commitments with job responsibilities, and many other issues.

## 2.1.1 Spectrum Nature of ASD

The word "spectrum" reflects the range of symptoms and abilities among individuals with autism. Some may require significant support, while others may function independently. This spectrum was recognized to emphasize the variability of the disorder (Lord et al., 2018).

1. High-functioning Autism: Often linked to Asperger syndrome, these individuals may have average to above-average intellectual capabilities, with fewer daily living challenges but still struggle with social nuances. Many individuals with high-functioning autism have average to above-average intellectual capabilities. They may excel in specific academic subjects or areas of interest, often referred to as "splinter skills" (Wing, 1996). They may find it difficult to engage in typical back-and-forth conversations, often dominating discussions with their interests (Landa et al., 2007).

Individuals may be relatively independent in daily living activities, such as personal hygiene and self-care. However, they might require support in managing social situations and emotional responses, particularly in unfamiliar or stressful environments.(Howlin,1998).Many individuals with high-functioning autism report sensory sensitivities, such as aversion to loud noises or certain textures, which can affect their comfort and ability to function in various settings (Ben-Sasson et al., 2009).

2. Low-functioning Autism: it refers to individuals who may have significant cognitive delays and require substantial support in daily activities. Individuals may present with significant intellectual disabilities, often defined as an IQ below 70, which impacts their ability to learn, adapt, and engage in typical educational environments (Lord et al., 2000).These individuals often require intensive support in daily living activities, including personal care, communication, and navigating social situations. They may rely on caregivers for assistance with tasks that others may complete independently, such as dressing, eating, or using the bathroom.(Schreibman et al., 2015).

# Psychological Experience of Parents of Children with Autism

Many low-functioning individuals may have limited verbal communication abilities, using alternative methods such as sign language, picture exchange systems, or communication devices. This can hinder their ability to express needs and desires, leading to frustration and behavioral outbursts (Tager-Flusberg & Kasari, 2013). Behavioral issues such as meltdowns or self-injurious behaviors may be more pronounced. These behaviors often stem from difficulties in communication, sensory overload, or changes in routine, necessitating comprehensive behavioral interventions (American Psychiatric Association, 2013). According to Hastings and Johnson (2001) there was association between higher levels of autism symptomatology and parental stress. Where the more severe the symptom, the greater is the degree of parental stress (Dunn et al., 2001).

## **2.1.2 Comorbidities in ASD**

Autism Spectrum Disorder (ASD) may occur independently, but it frequently coexists with various comorbid conditions that complicate diagnosis and treatment. Affecting approximately 40-70% of individuals with ASD, anxiety disorders—such as generalized anxiety and social anxiety—can significantly hinder a child's social interactions and daily functioning, leading to increased distress (Simonoff et al., 2008).

Present in 30-80% of children with autism, ADHD symptoms, such as inattention and hyperactivity, complicate educational settings and behavioral management, hindering academic performance (Sukhodolsky et al., 2008).

Approximately 30-40% of individuals with ASD also experience intellectual disabilities, which can affect cognitive development, adaptive functioning, and educational attainment (Eisenhower et al., 2005). Present in 20-30% of individuals with autism, epilepsy introduces additional health concerns that can disrupt learning and social interactions (Tuchman & Cuccaro, 2011).

The presence of comorbidities in children with ASD can lead to significant challenges, affecting both their development and their families. Parents often experience heightened stress and anxiety due to managing multiple comorbidities, leading to feelings of frustration and grief (Davis & Carter, 2008; Karst & Van Hecke, 2012). The costs associated with treating multiple conditions

# Psychological Experience of Parents of Children with Autism

can be overwhelming, leading to financial strain (Peters-Scheffer et al., 2011; Rosenberg et al., 2011).

## **2.2. Impact of Autism on Family Dynamics**

Studies suggest that family structure, parental education, socioeconomic status, geographic location and parental role play crucial roles in determining how parents manage challenges when raising a child with Autism.

Studies indicate that in nuclear families, parents often handle most of the caregiving, which can lead to increased stress and isolation, especially in rural areas. Despite this, the close family unit can foster strong bonds between parents and children with ASD (Hodgetts et al., 2014). While extended families, including grandparents and other relatives, provide additional emotional and physical support, such as respite care or financial help. However, they may face challenges in understanding ASD, potentially causing tension and complicate the relationship (Blacher & McIntyre, 2006).

Studies show parents with higher education levels tend to navigate the complexities of ASD better, seeking appropriate therapies, advocating for services, and actively engaging in their child's treatment (Parker et al., 2011). Parents with lower education levels may struggle with understanding the diagnosis and accessing resources, potentially leading to feelings of overwhelm and mental health challenges (Kogan et al., 2008).

According to Lund et al. (2018), families with lower socioeconomic status often face barriers like limited access to healthcare and therapy, financial stress, and fewer community resources, exacerbating the challenges of raising a child with ASD. On the other hand wealthier families typically have better access to specialized care, but may still face emotional challenges, including social stigma and pressure to meet high expectations for their child (Hodgetts et al., 2014).

Studies indicate parents in urban areas have access to a broader range of resources, including healthcare, therapy centers, and support groups, but may experience higher stress due to the pressures of city life (Mazefsky et al., 2014). On the other hand parents in rural areas often face

# Psychological Experience of Parents of Children with Autism

difficulties with limited access to resources and longer travel times for care. However, they may benefit from closer-knit communities and more local support (Myers & McCarty, 2015).

Studies show that mothers often take the primary caregiving role, which can lead to stress, burnout, and higher rates of depression. However, they are usually the main advocates for their child's care (Dardas & Ahmad, 2014; Totsika et al., 2011) this finding supported by Hastings and Johnson(2001) and Sivberg (2002) mothers of children with autism have been found to experience greater stress and difficulties in adjustment compared with mothers of children with other physical and intellectual difficulties and fathers of children with autism report more financial impact and disruption of family activities. Fathers may be less involved in daily caregiving due to work demands but play a critical supportive role in the family(Baker et al., 2011).

## **2.3. Psychological impacts**

### **2.3.1 Stress**

Studies showed that families with a child with neurodevelopmental disorder more stress than other families, either due to the manifestations of the child's particular physical needs and/or social dysfunction (Seltzer et al., 2004). Higher general stress levels have been reported in mothers of children with ASD than in those whose children had other conditions, such as undifferentiated developmental delays or genetic syndromes (Estes et al., 2009).

McConachie et al.(2005), suggested that mothers of had a much higher stress level than the general population which is mainly characterized by emotions including feelings of being overwhelmed, anger at their spouse, or themselves, despair at the incurable nature of the disorder, guilt ,frustration ,feelings of social isolation, embarrassment at child's behavior in public. A study done in India showed depression, anxiety, and stress, attributed to financial constraints, inadequate facilities, social and unnecessary family pressures were mostly recorded in mothers as compared to fathers (Bashir et al., 2014). The study also concluded that autism potentially influences the parents' psychological well-being (Bashir et al., 2014).

# Psychological Experience of Parents of Children with Autism

## **2.3.2 Depression**

A study showed prevalence of depressive disorders of 31% among parents of children with ASD. (Schnabel et al., 2020). Another study finding showed that parents who reported social acceptance as unmet-or-extremely-unmet needs had significantly higher levels of stress, anxiety, and depression symptoms, as compared to their counterparts (Estes et al., 2009). Schnabel et al. (2020), also showed important associations between the internalizing mental health problems of autistic youth and the depression symptoms of parents across time. Parents of children with ASD have also been found to report poorer health and more illnesses than parents of children with typical development and children with other disabilities (Smith et al., 2012).

Parents of children with autism endure higher stress levels, compared to an opposite scenario, and are also more pessimistic or skeptical about the future. Psychological distresses of caregivers of children with ASD (CASD) tend to be marked with gloomy mood, pessimism, anhedonia, and tendency for lack of initiative which often fall under the umbrella of depressive illness. Caregivers of children with ASD (CASD) tend to exhibit a higher magnitude of various spectra of depressive symptoms compared to caregivers of other developmental anomalies, or the general public (Lajiness et al., 2008).

Similarly Caregivers of children with ASD (CASD) report a high level of poor quality sleep (Lajiness et al., 2008). Following the diagnosis of their children parents experienced stress, depression, and anxiety (Al-Farsi et al., 2016).

## **2.3.3 Anxiety**

Another study among parents with ASD child in Australia showed majority of parents reported that they were sometimes unable to deal effectively with their child's behavior followed by being severely anxious and clinically depressed. On the other hand access to family support and parental health were major risk factors for depression and anxiety (Bitsika & Sharpley, 2004).

According to Williams and Wright (2007), parents with ASD children experience reactions including expressing guilt or worry about wrong actions during pregnancy or in motherhood, a sense of lost dreams and aspirations for the child, as well as fear of the future, and therefore tend to demand specific changes or adjustments, joining support communities to learn and share

# Psychological Experience of Parents of Children with Autism

various experiences after their child's diagnosis .On the other hand other families tend to avoid or ignore information about topics related to autism. This might be due to the inability to accept the child's condition or comprehend the prevailing situation (Williams and Wright, 2007).

The presence of a child with special needs such as autism spectrum disorder (ASD) in the household is likely to trigger “psychological burden” among significant others which often presents with catastrophic thinking and being anxious, as well as various somatic complaints such as breathing difficulties, pounding of the heart, and sweatiness of the palms. These complaints have been expressed as symptoms of anxiety disorders (Feinberg et al.,2014 ; Kuusikko et al., 2013).

## **2.3.4 Psychological impact of stigma**

Papadopoulos et al. found that autism-related stigma, including public stigma and internalized stigma, negatively impact informal caregivers' mental health, including depression, anxiety, and psychological distress (Papadopoulos et al., 2019).A study in Kazakhstan showed families experiences social rejection and stigma linked to autism in their community, in the mainstream health care, and in the educational systems (An S et al., 2018).

Another study by Demissie(2015), found that parents having child with autism expressed their feeling of being isolated from social life due to lack of understanding what autism is and what was involved in caring by the community. Similarly a study by Tekola et al. (2016), found that families of children with autism experience psychosocial challenges, including severe stigma. According to Kibreab (2021), having an autistic child has an impact on mothers in many ways including quitting a job, having limited social interaction, mood swings, and at times frustration.

## **2.4. Coping mechanisms**

### **2.4.1Acceptance**

A study in USA showed mothers with autistic children reported higher psychological well-being and the ability to reduce stress by accepting the child's condition, without being pressured or overburdened. Similarly a closer relationship with family and the environment, felt independent and positive to develop an emotional connection with the autistic children were reported by the study participants. These parents tend to manage inner thoughts and emotions in dealing with

# Psychological Experience of Parents of Children with Autism

various arising problems by establishing control over limitations, observing parenting demands in a broader perspective and initiating the optimum possible experiences (Dykens et al., 2014).

A 2023 study by Asmare et al. (2023), showed after experiencing prolonged emotional reactions and (re)defining the causes of ASD in their own terms, several participants commented that they accepted their child's status. They found acceptance particularly important in facilitating their emotional transition from despair to hope, boosting their resilience, developing coping strategies and adopting new mothering practices. Another study by Kibreab (2021), found that praying, consuming alcohol, crying, and accepting the case as a gift from God were identified as coping mechanisms by mothers to deal with challenges and stressful situations emanating from being a mother of an autistic child.

## **2.4.2 Resilience**

Resilience refers to an individual's ability for personal development to ensure an improved standard of living and also triggers the capacity to accomplish responsibilities and solve problems effectively (Gardner, 2020). It is a significant factor influencing psychological well-being. Mothers with high resilience will not focus on disappointment, sadness, and shame, but on searching for alternative solutions. Meanwhile, poor resilience can cause overwhelming situations, resulting in inadequate management of child's conditions. Mentally stable parents in a position to meet these special needs, are not expected to drown in loneliness and isolation, known to adversely affect families and disrupt composure (Kavaliotis, 2017).

## **2.4.3 Religiosity**

Religiosity refers to an absolute relationship between humans and Gods, resulting in total dependence on the ability to meet daily provisions, both physically and spiritually. Individuals with strong religious beliefs reported extensive life satisfaction, sufficient personal happiness, and lower negative impacts of traumatic events, compared to the normal state and are expected to accept God's overall decisions (Elosúa, 2015). Studies also showed parents of children with autism spectrum disorders confirmed a relationship between religious values and parental resilience (Kavaliotis, 2017).

# Psychological Experience of Parents of Children with Autism

## **2.4.4 Emotion focused coping**

Emotion focused coping includes support from family, friends, social support groups, other parents of children with ASD, service providers, advocacy, and religion (Lai et al., 2015) and confrontation, self-control, and escape (Sivberg, 2002 ).

## **2.4.5 Positive perceptions**

Positive perceptions has viral effect in the coping process and dealing with the stressful events (Folkman & Moskowitz, 2000).Essentially, positive perceptions are different outcomes to stress and other negative experiences but they occur in conjunction with the negative or stressful experiences. Positive affect might help to strengthen both psychological and physical resources during stress, act as a protector from the adverse physiological consequences of stress and help to protect against clinical depression (Folkman & Mosokowitz,2000). Different studies suggest that positive perceptions play a central role in the coping process. It has been proposed that positive perceptions may assist us to cope better with the traumatic and stressful events (Taylor, 1983).

## **2.5 Service availability**

Montes and Halterman,(2009), concluded that parents of children with ASDs reported less access to and dissatisfaction with school and community health services where a study which includes 486 parents who lived in the United States, Canada, Australia, New Zealand, England, and Ireland found that 70 % of parents dislike the treatments provided for their children. In this regard, parents of children with autism are left with the most demanding challenges that require them, on the one hand, to make decisions regarding the type of therapies and the criteria to implement and determine the effectiveness of these therapies. This challenge might be more problematic, especially in the absence of well-established consensus regarding appropriate educational practices (Dunlap &Iovannone, 2008).

A study among Omani children indicated that readily available autism services are of paramount importance in order to provide adequate rehabilitation of affected children and their families and improve their quality of life (Al-Farsi et al., 2013). A similar study Saudi Arabia showed that significant deficiencies exist in the availability of autism services the region. Access for referrals for important services is also limited similarly there was lack of provision of adequate sources of

## Psychological Experience of Parents of Children with Autism

financial, counselling and support for families of children with ASD.. The study also identified several areas that can be targeted to help develop, promote, and improve the provided services for children with autism spectrum disorder (Babatin et al., 2013). A study conducted among Palestinian in the West Bank reported limited or denied access to education, community-based services, and ASD-specific interventions. Consequently, several families noted their children did not receive any services whatsoever (Dababnah & Bulson, 2015).

A study in Oman also showed significant deficiencies in the availability of autism services in the region with limited access to outside referrals for deficient services, as perceived by the professionals working in these centers. Up to 57% of the study participants identified important and needed services that were not available at their center (Al-Farsi et al., 2013). A study conducted in Jordan among Parents showed an average satisfaction with the received services. Issues regarding the cost of services, parents-professional partnerships, and overall quality of services were seen by parents as sources of low satisfaction. On the other hand, parents expressed the need for early intervention, family counseling, and community awareness services (Al Jabery et al., 2014).

In Ethiopia a study showed the large majority of parents indicated they were unaware of the services provided to their children and indicated poor parent–agency coordination. Parents noted very limited formal support systems to help cope with the stigma of having a child with ASD (Zelege et al., 2018). Another study in Ethiopia also showed inaccessibility of health professionals specialized in childhood developmental disorders and the lack of proper treatment were exhausting to parents, lack of facilities designed to accommodate children with disorders such as autism were reported (Gebre,2016).

# Psychological Experience of Parents of Children with Autism

## CHAPTER THREE

### METHODOLOGY

The study used a qualitative methodology to gather relevant data and information from the parents of autistic children. It is assumed that qualitative methodology is highly relevant to meet the study objectives, to get the required information, and to undertake a deep exploration of the views and lived experience of parents of autistic children.

#### 3.1 The Study Design

Institutional based qualitative study design with in-depth interview was used to explore the psychological experience of parents with autistic children at St Paul Hospital Millennium Medical College. Based on the assumption, that qualitative method is highly relevant to meet the study objectives, to get the required information, and to undertake a deep exploration of the views and lived experience of parents of autistic children.

From the qualitative method, a phenomenological approach was employed for this study. Phenomenology as a qualitative methodology enabled the participants to share their experiences and voice their concerns. The phenomenological approach entails finding the meaning in human experiences, as related by the participants in the situation. The process will allow the researcher to understand the perspectives of study participants, as recounted by the participants themselves. A phenomenological approach is also suitable for understanding subjective experiences, and understanding what motivates people to behave in a certain manner. The phenomenological approach is the best way to understand different parents of autistic children who have common or shared psychological experience about autism on their wellbeing.

#### 3.2 Study area and period

The study was conducted in St. Paul Hospital Millennium Medical College. St. Paul's Hospital was built in 1969 (was named St Paul General Specialized Hospital until 2008) by Emperor Haile Selassie in collaboration with the German Evangelical Church, as a source of medical care for underserved populations. It currently has 700 beds, with an annual average of 200,000

# Psychological Experience of Parents of Children with Autism

patients and a catchment population of more than 5 million. Approximately 75% of the patients receive medical services free of charge. There is over 2800 clinical and non-clinical staff in over 13 departments, most recently launching its new haemodialysis unit and the country's National Kidney Transplant Centre.

Among the three governmental hospitals in Ethiopia that offer child psychiatry services, St. Paul's Hospital Millennium Medical College is recognized as the leading institution. It provides comprehensive child and adolescent psychiatric care, and approximately 50 percent of the population seeking mental health services for children and adolescents follows up at this hospital.

The study was conducted from 1st -30th August 2024.

## **3.3 Population**

**3.3.1 Source Population:** All parents of children with autism attending Psychiatry department for their children at St. Paul Hospital Millennium Medical College, Addis Ababa, Ethiopia. At the time of data collection there were 15 parents presented, the data collection were continued and 9 parents interviewed until saturation reached.

**3.3.2 Study Population:** Selected parents of children with autism who came for follow up for their children at St Paul's hospital, child psychiatry clinic and who fulfill the inclusion criteria.at the time of data collection 9 parents were interviewed until data saturation.

## **3.4 inclusion and exclusion criteria**

**3.4.1 Inclusion criteria:** parents of children with autism who are attending child psychiatry clinic regularly for their children at St Paul hospital, participants who are willing to share their experience, and Participants who are residents of Addis Ababa was included in the study.

**3.4.2 Exclusion criteria:** parents of children with autism who are severely sick during the data collection period were excluded.

## **3.5 Sample size and sampling technique**

Purposive sampling technique was used. Participants were selected from parents with autism children on follow up at St. Paul's hospital, Addis Ababa, Ethiopia.

# Psychological Experience of Parents of Children with Autism

To start with, nine parents with autism children were selected for the study. But the sample size was determined depending on the data saturation. Meeting appointment was made with participants who accepted to participate in the study.

## **3.6 Data Collection Topic Guides**

Semi-structured interview guide was prepared by the researcher from the available literature and own personal experience to explore the socio-demographic characteristics and experiences of parents with children diagnosed with autism.

Once the interview guide questions prepared, it translated to the local language Amharic and re-translated to English by linguistic graduates. Discussion was made with peers together with the researcher. Finally detailed clarifications were given on matters that needed a brief explanation. Also the interview guide was commented and reshaped by the advisor, in addition to peers to assure that each item was in line with the stated research objective. The interview guide included participant's socio-demographic characteristics and experience of parents related children with autism.

Data was collected by three experienced health care professionals (Psychiatry Nurse) from 1<sup>st</sup> August -30<sup>th</sup> 2024. Individual interview was used to collect experience of parents of children with autism. The data was collected in a quiet environment in a separate room to avoid disruption from other patients and visitors. The interview was recorded with audio-recording device. Each interview was approximately 30-40 minute long, allowing for in-depth exploration of participants' experiences.

A separate sheet of paper was used for each interview to record the socio-demographic data of each participant. Informed consent was obtained from all participants, and ethical approval was secured for initiation of the study. Participants name will not be recorded or written anywhere to ensure confidentiality.

The recorded audio were stored and transcribed by the researcher. The transcriptions analyzed using thematic analysis to identify key themes and patterns in the experiences shared by participants.

# Psychological Experience of Parents of Children with Autism

## **3.7 Data Quality Assurance**

To ensure the quality of data reflexivity were employed. The study was maintained by using collecting rich data by careful interview of individuals (single parent) and using the multi-method strategy of data collection, which consists; in-depth interviews. Reviewing of the interview guide by advisor and peers those who have experience on the area of qualitative study; Member check of the analysis result is made to check that the analysis result is exactly as participants experiences before writing of final result report by inviting to read the translated data for study parents. All nine interviews were audio-recorded and noted on a hard copy to provide back up.

## **3.8 Method of Data Analysis**

Data collected from participants was thematically grouped, transcribed, organized, and analyzed. For the purpose of this study Phenomenological approach were used which enabled the participants to share their experiences and concerns. In doing so, the thoughts, feelings, emotions, and beliefs of participants have been emphasized. The obtained interview data was translated directly from the parents' mother tongue to the English version by the researcher with the consultation of the advisor. Study findings were coded like parent 1, 2, 3.....9. Finally, major findings categorized into the following major themes these are: psychological experience, service availability, and the coping strategies.

## **3.9 Ethical Considerations**

Ethical clearance was first obtained Addis Ababa University research Ethical Review board Committee and of the School of Psychology and concerned others to obtain permission and cooperation during the data collection process. Then, the letters was taken to the respective St Paul Hospital Millennium Medical collage to obtain ethical clearance to conduct the study. Informed oral consent was obtained from each study subject prior to the data collection process after the purpose of study has been explained and they become briefed about the confidentiality of their responses and the importance of providing the right information to help the study achieve its objective. All participants were asked for their willingness to participate in the study and were told that it will not have any risk on them. Confidentiality of the information was assured and privacy of the respondent was maintained.

# Psychological Experience of Parents of Children with Autism

## CHAPTER FOUR

### RESULT

This chapter presents the findings from interviews conducted with parents of children diagnosed with ASD. The aim was to understand the psychological experiences they encounter, coping mechanisms they used and the availability service for them. The study involved 9 parents; 6 mothers and 3 fathers, with children aged between 5 and 16 years diagnosed with ASD. Participants have different demographic background. The data were collected through in-depth, semi structured interview which allowed parents to share their experiences in their own words. Thematic analysis was employed to identify major themes. The major themes are psychological experience, coping mechanism and service availability with related subthemes.

#### 1. Demographic Data

This table shows the respondents age, gender, marital status, educational status, occupation, relationship with child and sex of child, age of child and level of ASD of autistic child of the respondents at St. Paulo's Hospital Millennium Medical College 2024.

PARENT( CARE GIVER )	Age of parent	Gender of parent	Marital Status	Relationship with child	Educational status	Sex of child	Age of child	Level of ASD
1.	31	Female	Married	Mother	Diploma	M	8	2
2.	42	Male	Married	Father	12 <sup>th</sup>	F	8	2
3.	45	Female	Married	Mother	10 <sup>th</sup>	M	12	1
4.	35	Female	Divorced	Mother	6 <sup>th</sup>	M	16	2
5.	35	Female	Married	Mother	7 <sup>th</sup>	F	8	2

# Psychological Experience of Parents of Children with Autism

6.	32	Female	Married	Mother	8 <sup>th</sup>	F	7	1
7.	35	Male	Separated	Father	12 <sup>th</sup>	F	5	1
8.	34	Male	Married	Father	Degree	M	6	2
9.	47	Female	Separated	Mother	MSc, MA	M	6	1

## 2. Psychological experience

In this study parents shared their psychological experiences due to having autistic children. They reveal how they experienced anxiety, stress and other psychological experience including anger and self-isolation. They also mention how those psychological problems affect their life significantly.

### 2.1 Anxiety

Having a child with autism leads Parents to feel anxious, fear, tensioned and persistently worried. They get tensioned and nervous when they heard about their child's diagnosis for the first time and as their child getting older their worries tend to increase.

Parent express their worries about long-term well-being and future independence of their children, if they were no longer able to care for them. For example,

**Parent 2** stated

*"Until she was four years old, I didn't know she had autism, until my wife insisted that we go to the hospital. The doctor then informed us of her diagnosis, and in that moment, I felt confused because I have not heard about autism before. Because of my child's condition, I cannot let her go to school alone for fear that something might happen to her. I am responsible for picking her up from school, which causes me to lose customers. I no longer spend time with my friends like I used to because I have to take care of my child, which shifts my attention entirely to her.*

## Psychological Experience of Parents of Children with Autism

*I feel very sad when I see that my child cannot interact with other children. I constantly worry about her future; if something happens to us, who will take responsibility for her? I am afraid to take her into the neighborhood for fear that she might do something inappropriate, which stresses me out at times. What else can I do? This is from Allah, and I must accept her condition."*

**Parent 3** shared similar statement

*"I took my child to the hospital when he was 2 years old because he was unable to say 'mom' or 'dad' and did not engage with us. I decided to go to the hospital to see if there was a problem. The doctors diagnosed him with autism, and I was shocked and saddened by the news. After that, I stopped visiting that hospital because I couldn't believe his condition. As he gets older, I worry about what will happen to him. It's difficult to leave him alone anywhere at any time. My husband always helps me in this journey but I sometimes cry out because of the frustration "*

Parents express fear of having another child due to concerns that they may have another child with autism. For example, **Parent 1** stated

*"I have four children, and my firstborn has autism. I didn't notice it until he was two years old. He lives in his own world, prefers to do things by himself, and becomes aggressive if he doesn't get what he wants. I took him to the hospital, where the doctor told me he has autism. In that moment, I felt confused. When they explained autism to me, I couldn't accept it; I felt very sad and overwhelmed for almost a year. I was very anxious to be pregnant due to fear of birthing another child with the same condition. Even after birth I was not stable mentally like a sick person and I followed every developmental stage of my second born child and the same thing makes me worry until now, even after I birth my 4<sup>th</sup> child. My husband is very supportive, he strengthen me every time. I try to suppress my emotion to cope with the challenges"*

Parents indicated that their anxiety is exacerbated by frequently feeling sad about their child's behavior. For instance, their children may struggle to communicate easily, unlike typical children, and often cannot express themselves or engage with other children. This situation contributes to parents' sadness and increases their levels of anxiety. Both fathers and mothers of children with autism are equally affected by these circumstances, with many fathers increasingly taking on caregiving responsibilities traditionally associated with mothers. For example,

# Psychological Experience of Parents of Children with Autism

**Parent 8** shared

*"My wife and I have one child, and he has autism. My wife was the first to care for him, but she became very distressed when she heard about his diagnosis. His behaviour can be very challenging, and after some time, she stopped everything. Now, I do everything for him and try many different approaches to support him, but I feel alone on this journey. Since he cannot express his needs properly; including when he is hungry, it makes me very sad and worried. I was recently diagnosed with hypertension, and the doctors told me to avoid stress, but I find it difficult because I worry so much about my son's condition. I am struggling with these challenges and coping by suppressing my emotions"*

**Parent 1** also stated similar statement

*"I felt very sad because of my child's behavior. I cannot take him out to birthday parties or other events, even though I want to, and that makes it difficult for both of us which makes me worry a lot. "*

## **2.2 Stress**

Parents often experience significant stress due to various challenges associated with parental responsibility, child's special needs, and shortages of services.

Parents indicate that parental responsibilities fall on both fathers and mothers. These responsibilities include taking care of a child, transporting them to school, and engaging in other activities. However, the nature of these responsibilities differs when it comes to children with autism such as: they have to find suitable schools, they may have to prepare specific types of meals and find toys and activities that support their child's engagement. These specific needs of children with ASD lead them to stress and overwhelm due to unaffordability of those needs. For instance,

**Parent 2** stated the following

*"Her mother stops working to taking care of her and we have other children but we almost spend our money on our autistic child because she has additional demands which is overwhelming"*

# Psychological Experience of Parents of Children with Autism

**Parent 8** stated similar concern

*"I couldn't find a suitable school for my son due to both unavailability and cost, which has stressed me out. I have taken him to at least five schools, and they charge me extra because he is a special needs student. I pay up to 60-70% of my total income in school fees, and I worry about my future if this situation continues."*

Parents also indicate that they became less care about themselves related to the stress they encountered and that shifts their focus to their child.as an example

**Parent 4** stated the following

*"I have four children and I am divorced.am still don't understand the things about autism.my husband didn't help me and am struggling lonely and also I have cancer imagine how hard it's for me.am raising 4 children alone and one has autism. I don't give any attention for myself; I raised him by myself along with his 3 siblings"*

## **2.3 other psychological experiences**

Parents indicate that being misunderstood by their family members and the community, along with their child's behavior, leads them to feel anger and self-isolation.

### **1. Anger**

Parents reported that they get angry when a family member does not understand their child's condition. For example,

**Parent 1** stated

*"I felt very angry when my relatives spread false information about my son's condition which makes another family members frightened and sees my son as crazy person"*

**Parent 4** similar concern

*"My husband always says, 'My son is autistic because of a curse in your family.' This makes me very angry."*

# Psychological Experience of Parents of Children with Autism

## 2. Self-isolation

Parents also mentioned how difficult it is to engage with the community due to their child's unusual behavior. The comments they receive from others lead them to isolate themselves from the community. For example,

**Parent 9** stated

*"I have 3 children and one has autism he is a second child. He has brilliant mind but his behavior is very difficult to manage. I isolated myself from sociable activities due to being stressed out about raising questions and comments from the community for example when they saw him restless they say hold him in judgmental way or they would say he is a gloomy child. i cope the challenges by prayer and strengthening my hope that God will do something for him"*

## 3. Coping Methods

Parents used various coping strategies to manage their stress, anxiety and other psychological problems which include acceptance, religion, and emotion focused coping and resilience.

### 3.1 Acceptance

Parents reported that after they encountered psychological problems they find acceptance as a solution. They also expressed how get emotional relief and hope after they accept their child's condition. For example,

**Parent 5** responded as

*"I was shocked when I heard my daughter has autism because I had always heard that it was a curse, and I had no knowledge about it. I used to cry because of her condition, but now, as a coping method, I try to accept it. I repeatedly watch YouTube videos and see people who have worse conditions than mine. I believe that Allah has tested me for a good reason."*

### 3.2 Religion

Parents express how engaging in religious practices give hope and strength and they became viewing their child as a gift from God. For example,

# Psychological Experience of Parents of Children with Autism

**Parent 9** explained as

*"Religion plays an important role in my life. I believe that everything God has given us has a purpose, and I hope that God can heal my son. I take him to places of prayer and use holy water, which helps me a lot."*

## **3.3 Emotion focused coping**

Parents used emotion focused coping which includes engage in support groups or informal networks which help them to share their experience with each other which help them relief and process their stress and crying as response for emotional stress. For example,

**Parent 2** stated the following

*"I have Monthly meeting with other parents of children with autisamat Paulo's hospital and we shared our experience there, it helps me to feel am not the only one who struggled and get sense of familiarity"*

Parents reported that they used crying when they get overwhelmed and feel helpless by the situation to alleviate there stress. For example

**Parent 6** stated the following

*"I have one daughter, and she has autism. She is different from other children, and I was not surprised because my pregnancy was not normal, and I believed there was something wrong with her. I went to the hospital for treatment, and then the doctor told me she has autism. I asked around to learn more about it, and they explained her condition to me. I face many challenges and frustrations due to the lack of improvement in my child's condition. I cope with these challenges by crying. What else can I do? She is my daughter, and I feel like there are no other options."*

## **3.4 Resilience**

Parents mentioned that despite the psychological experience they encountered, they develop resilience and expressing hope for their child's future and try to create awareness on the understanding of ASD. For example,

# Psychological Experience of Parents of Children with Autism

**Parent 3** stated the following

"I remind myself to be strong and I am actively trying to raise awareness about my son's condition."

Parents also explained how accepting their child's condition increased their resilience .for example

**Parent 5** explained as follows

*"I used to afraid to talk about my child's condition but now am accepting her condition and am no longer ashamed when people ask me about her."*

## **3.4 Complaint to government officials by letter**

Parents indicated that writing letters to government officials such as ministry of education, ministry of health, human rights commission and ministry of women and children which create a sense of empowerment. This shows the importance of active involvement, where parents seek to influence policy and advocate for better resources.

**Parent 9** shared her experience

*"We have monthly meetings at Paulo's Hospital where we discuss how to overcome the challenges we are facing. During one meeting, we decided to write a letter focusing on education, medication supplies, and community awareness. We attached the signatures of 100 parents and selected committee members, of which I am one. We visited various offices to speak with officials, and they promised to help us, which gave us hope. "*

## **4. Service availability**

Parents faced several challenges due to shortages of services. They reported their frustration and struggles with the lack of services in healthcare, schools, and other community services, as well as the limited support they received. They expressed their concerns based on various encounters, which are as follows:

# Psychological Experience of Parents of Children with Autism

## **4.1 Access for family intervention service at health care service**

Parents reported different experiences about the family intervention service which includes training and education access, organized support group and any emotional or psychological support from health care professionals. In addition to this parents also concerned about inconsistency of this services.

### **1. Access of Parental skill training and education**

Parents indicated having different experience about parental skill training access. They reported as follows:

Parent 2, 3, 8 and 9 reported that they got parental skill training at St. Paulo's Hospital Millennium Medical College

Parents 1, 4, 6, and 7 reported they did not receive parental skill training

Differently Parent 5 encounters bad experience at health care service. She explained as follows:

*"I did not receive any training. However, I had a negative experience related to caregiver skill training (CST). I visited a clinic in Gojamberenda to seek CST, but the doctor assigned to me treated us carelessly. She barely examined my daughter and suggested some techniques in just five minutes. Then, she said she would call me for a follow-up appointment, but I never received a call. "*

### **2. Psychological and emotional support from health care professionals**

Psychological or emotional support from health care professionals is limited. Only parent 4 and 9 stated that they have received psychological or emotional support from health care professionals.

### **3. Availability of support group**

The availability of support groups varied between parents. Some of them have support groups. For example,

Parent 2, 3, 6 and 9 reported that they have well organized support group at Paulo's Hospital Millennium Medical College, they attends the meeting monthly.

# Psychological Experience of Parents of Children with Autism

The other parents reported that they have no any organized support group.

## **4.2 Support from governmental and nongovernmental organizations**

There is none parental focused support from governmental and non-governmental organizations. Parents stated that they did not get any support from governmental and nongovernmental bodies.

## **4.3 Needs of parents at community and governmental level**

Parents stated that they have so many struggles which are related to unavailability of school services and its affordability. They also added some suggestions where the limited knowledge about autism among health care professionals and community should be addressed.

Parents indicated that most of governmental schools have poor quality and the private once are very expensive.

**Parent 5** said

*"I suggest that autistic children be treated equally and given the same opportunities as everyone else in the community. We are frustrated by the lack of available schools for autistic children, so I recommend that more special needs schools to be established. Many families cannot afford the fees for private schools."*

Parents indicated that if the educational curriculum should be reviewed

**Parent 9** stated as follows

*"The educational curriculum should be reviewed to ensure it is appropriate for autistic children. Currently, our educational system is primarily teacher-focused, which is often uncomfortable for these children. Additional activities, such as music and art, are needed to help nurture their unique talents. Since autistic children may struggle to focus on one task for extended periods, increasing the number of teachers can be beneficial. More teachers can provide the necessary attention to each child, creating a more supportive and effective learning environment for both students and educators"*

## Psychological Experience of Parents of Children with Autism

Parents are suggesting the necessity of training for health care professionals and create awareness about autism for the community

### **Parent 9** Added

*"We cannot assume that every health professional has sufficient knowledge about autism. For instance, when I took my child to the laboratory for tests, he became unstable, and the assigned nurse shouted and judged me as if I had raised him inappropriately. This highlights the need for training for healthcare professionals. Additionally, there should be awareness campaigns in the community, such as broadcasts, to educate people about autism and its impact on parents. "*

Parents reported that they need medication support for their children, as they mentioned that they often do not get the prescribed medications from pharmacy due to high costs or affordability issues or absence in the local market. For example

### **Parent 4** shared

*"I couldn't find the right medication for my child, who is now 16 years old. It is very difficult to manage his behaviour without a medication. The doctors prescribed the medication, but I can't afford it, and sometimes it is unavailable at the pharmacy."*

Parent 9 and 1 shared similar statement

# Psychological Experience of Parents of Children with Autism

## CHAPTER FIVE

### DISCUSSION

In this chapter, major findings of the study are discussed based on the major themes includes Psychological experience, Service availability and Coping mechanisms.

#### **5.1 Psychological Experience**

In this study the parents mentioned some psychological experience they faced because they have child with autism which includes anxiety, stress, being worried, sadness, fear, anger, self-isolation and poor self-care. Nearly all participants were highly worried and stressed about the future life of their child; some of them were pessimistic about the future. This finding is consistent with the study by Lajiness et al. (2008), where parents of children with autism endure higher stress levels, compared to an opposite scenario, and are also more pessimistic or skeptical about the future. In my study due to having child with autism participants have poor relationship with others and which affects their psychological well-being. This finding is consistent with a study by Papadopoulos et al.(2019), where parents of children with autism experienced some psychological problems which are related to social and economic shortages while raising and supporting their children. Similarly a study by Tekola et al.(2016), found that families of children with autism experience psychosocial challenges, including severe stigma. Both fathers and mothers of children with autism are equally influenced by their circumstances, with many fathers increasingly taking on caregiving responsibilities traditionally associated with mothers. It consistent with a study by McStay et al. (2015), raising a child with autism can lead to various family adaptations and both fathers and mothers are equally influenced by their circumstances. Those psychological problems might be due to lack of support whether from family or community, unawareness in the community about ASD and the shortage of service.

#### **5.2 Service Availability**

This study also found out those services like educational facilities and health care service were not sufficiently available for this population. This finding is consistent with a study in US by Montes et al. (2009) where parents of children with ASDs reported less access to and dissatisfaction with school and community health services. Another study conducted among

## Psychological Experience of Parents of Children with Autism

Palestinians parents who raising children with autism spectrum disorder (ASD) in the West Bank reported limited or denied access to education, community-based services, and ASD-specific interventions (Dababnah & Bulson,2015).similarly A study in Addis Ababa reported that the majority of caregivers/parents reported unmet needs regarding their child's educational provision and others also indicated an unmet need for support from health professionals(Tilahunet al., 2016).

This study also found that parents not supported by both governmental and nongovernmental organizations and this can tell parents are experiencing lack of recognition by this organization. This finding is consistent with a study conducted in Ethiopia reported that like other African countries has limited autism service in governmental and nongovernmental levels (Tekola et al.,2016).This problem might be due to neglect of the issue by the government and non-governmental bodies.

### **5.2.1 Unavailability of Community-based and Family Intervention Services**

This study showed that some of the caregivers got the opportunity to participate in the parenting training organized by St Paul hospital and the training events opened a platform for the participants to exchange their ideas and discuss their situations among themselves. This training also limited at Paulo's Hospital. This shortage of service is consistent with a study where there has been severe shortage of services for children with autism in Ethiopia; access to services is further impeded by negative beliefs and stigmatizing attitudes towards affected children and their families (Tilahun et al., 2016).

This study also found out that family support systems i.e. Family and social supports, community-based programs, and family intervention services were not available for this population. This finding is consistent with another study in Ethiopia showed that children with autism spectrum disorders (ASDs) who were enrolled in intervention underserved due to a dearth of available professionals, low number of training facilities, and inadequate resources for family support (Zelege et al., 2018).This issue might be due to lack of qualified health professionals, educators or trainers to provide necessary support.

# Psychological Experience of Parents of Children with Autism

## 5.2.3 Need of parents at community and government level

Parents reported that they need an access to schools equipped with specialized resources, such as suitable class room, trained staff and tailored programs. Parents also indicate that schools should have the necessary tools and support systems to meet the unique needs of children with autism. This finding supported by McStay, Trembath, and Dissanayake(2015) indicated that parents face significant challenges in adapting to their child's needs and highlighted the importance of support systems, including access to specialized services and educational resources. Parents indicate that a review of the educational curriculum to better fit the needs of children with autism. This involves adding autism awareness and modified teaching methods to school programs.

Parents also strongly requested training for healthcare professionals to improve their understanding of autism and the specific needs of affected families which consisted with the study by Dempsey and Dunst (2004) the need for training healthcare professionals to better engage parents and understand their perspectives, ultimately improving the support provided to families.

They also emphasize the importance of raising awareness about autism within the community. Increased understanding can lead to better social integration for children with autism and reduce stigma, which is crucial for their overall development which is supported by Fombonne (2009) found that autism is a complex condition with varying prevalence rates across different populations. The study underscored the importance of community awareness and understanding of autism.

Parents also mentioned the necessity for accessible healthcare services that meet specifically to the needs of children with autism. This includes mental health services and medication supplements. Consisted with the study reported a systematic review focused on parent-mediated interventions for young children with autism which indicated such interventions can be effective in improving child outcomes (Oono, Honey, & McConachie, 2013)

## 5.3 Coping Strategies

**5.3.1 Religion:** in this study parents cope with the situation by praying to God or Allah and by hoping God or Allah doing something for their children. This finding similar with a study by

## Psychological Experience of Parents of Children with Autism

Kavaliotis (2017), shows that parents of children with autism spectrum disorders confirmed a relationship between religious values and parental resilience. Similarly in India which found that intervening factors like optimism, faith in gods, and religious support help to alleviate the degree of stress and to cope with the physical and emotional aspects of caregiving among parents having ASDs children (Kogan et al., 2008).

They might be used this strategy due to the religious communities provide support and the belief itself encourages resilience.

### **5.3.2 Acceptance and Resilience:**

In this study parents cope with the situation by accepting the condition of their child. This finding is consistent with a study in USA showed mothers with autistic children reported higher psychological well-being and the ability to reduce stress by accepting the child's condition, without being pressured or overburdened. (Dykens et al., 2014).

Parents also reported that developing resilience helped them to alleviate their stress and to be unashamed about their child's condition. This finding is similar with another study by Kavaliotis (2017), stated that mothers with high resilience will not focus on disappointment, sadness, and shame, but on searching for alternative solutions. Meanwhile, poor resilience can cause overwhelming situations, resulting in inadequate management of child's conditions. Where mentally stable parents in a position to meet these special needs, are not expected to drown in loneliness and isolation, known to adversely affect families and disrupt composure.

Parents also reported that acceptance of their child's condition also increases their resiliency. This finding is also similar with another study by Asmare et al. (2023), showed after experiencing prolonged emotional reactions and (re)defining the causes of ASD in their own terms, several participants commented that they accepted their child's status. They found acceptance particularly important in facilitating their emotional transition from despair to hope, boosting their resilience, developing coping strategies and adopting new mothering practices. They might be used this strategy to reduce stress and notice the difference after using it.

# Psychological Experience of Parents of Children with Autism

## **5.3.3 Emotion focused coping**

In this study parents indicated that they tried to search social groups who have similar case like them, as they stated it helps them to share their experience each other and get emotional bonding. This finding is consistent with Lai et al. (2015) Emotion focused coping includes finding support from family, friends, and social support groups, other parents of children with ASD and service providers. Similarly, parents stated that they use crying as an emotion focused coping strategy to express and process their feelings of sadness, frustration, or overwhelm. This finding is similar to a study by Sid and Kumar (2022) most parents with ASD child use Emotion Focused Coping Strategies which includes crying and visiting Spiritual Places. They might use this strategy to reduce stress and get a sense of relief.

## **5.3.4 Complaint to government officials by letter**

Parents indicated that writing letters to government officials such as the ministry of education, ministry of health, human rights commission and ministry of women and children which create a sense of empowerment. This shows the importance of active involvement, where parents seek to influence policy and advocate for better resources. This finding is also supported by Broadhurst & Holt (2010), how advocacy can reshape interactions between parents and local authorities, emphasizing the importance of effective communication in social services.

## CHAPTER SIX

### CONCLUSION AND RECOMMENDATION

#### 6.1 Conclusion

This research highlights the psychological experiences of parents raising children with autism at St. Paulo's Hospital Millennium Medical College. The psychological experiences of nine parents were explored using in-depth interview. The findings reveal that these parents often face significant psychological issues including stress, anxiety, worry, self-isolation, poor self-care, anger and sadness. Both mother and father equally affected by their child's condition.

Cultural perceptions and shortage of services further exacerbate these challenges, impacting the mental health and well-being of parents. Despite these difficulties, parents of children with autism often employ various coping mechanisms to manage the emotional and practical challenges, those strategies includes religious faith and practice, acceptance, resilience and emotion focused coping and Complaint to government officials by letter.

More over parents also expressed their frustration with the inadequate educational and health care services. The lack of those supportive systems contributes for their stress and feeling of being overwhelmed which point out the urgent need for systemic improvements.

In summary, this study signifies the need for improved support systems for parents of children with autism, emphasizing the importance of addressing both their psychological needs and the societal factors that influence their experiences.

#### 6.2 Recommendation

Based on the findings of this study the following recommendations are suggested to enhance the well-being of parents of children with autism

- Organize community events that encourage interactions between families of children with autism and the broader community, promoting acceptance and understanding. This can be

## Psychological Experience of Parents of Children with Autism

applicable through awareness campaigns, social gatherings and also collaboration of organizations or schools.

- Adequate educational facilities and health care service has to be available for parents who raising children with Autism and the government agencies are responsible to allocate funding and resources. Additionally policy should be developed to improve access to services and protect the rights of individuals with autism.
- Mental health professionals should take the lead in developing and delivering targeted mental health programs and services that specifically address the challenges faced by parents of children with autism. This includes offering counseling, establishing local or online support groups and facilitating regular meetings.

# Psychological Experience of Parents of Children with Autism

## REFERENCES

Al Jabery, M. A., Arabiat, D. H., Al Khamra, H. A., Betawi, I. A., & Abdel Jabbar, S. K. (2014). Parental perceptions of services provided for children with autism in Jordan. *Journal of Child and Family Studies, 23*, 475-486.

Alfandari, R. (2019). Legal Advocacy for Parents in Child Protection: Not a Question of If, but a Question of How. *The British Journal of Social Work, 49*(6), 1601-1618.

Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbati, M. M., & Al-Adawi, S. (2016). Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case-control study. *Neuropsychiatric disease and treatment, 1943-1951*.

Al-Farsi, Y. M., Waly, M. I., Al-Sharbati, M. M., Al-Shafae, M., Al-Farsi, O., Al-Fahdi, S., ...& Al-Adawi, S. (2013). Variation in socio-economic burden for caring of children with autism spectrum disorder in Oman: caregiver perspectives. *Journal of autism and developmental disorders, 43*, 1214-1221.

Alshaigi, K., Albraheem, R., Alsaleem, K., Zakaria, M., Jobeir, A., & Aldhalaan, H. (2020). Stigmatization among parents of autism spectrum disorder children in Riyadh, Saudi Arabia. *International Journal of Pediatrics and Adolescent Medicine, 7*(3), 140-146.

Amr, M., Ali, W. B., Hablas, H., Raddad, D., El-Mehesh, F., El-Gilany, A. H., & Al-Shamy, H. (2012). Sociodemographic factors in Arab children with autism spectrum disorders. *Pan African Medical Journal, 13*(1).

An, S., Chan, C. K., & Kaukenova, B. (2020). Families in transition: Parental perspectives of support and services for children with autism in Kazakhstan. *International Journal of Disability, Development and Education, 67*(1), 28-44.

# Psychological Experience of Parents of Children with Autism

Asmare, R. F., Taye, F. N., Kotecho, M. G., Mishna, F., &Regehr, C. (2023). Towards a “new mothering” practice? The life experiences of mothers raising a child with autism in urban Ethiopia. *International Journal of Environmental Research and Public Health*, 20(7), 5333.

Babatin, A. M., Alzahrani, B. S., Jan, F. M., Alkarimi, E. H., & Jan, M. M. (2016). The availability of services for children with autism spectrum disorder in a Saudi population. *Neurosciences Journal*, 21(3), 223-226.

Baio, J. (2018). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR. Surveillance Summaries*, 67.

Bakare, M. O., &Munir, K. M. (2011). Excess of non-verbal cases of autism spectrum disorders presenting to orthodox clinical practice in Africa—a trend possibly resulting from late diagnosis and intervention. *South African Journal of Psychiatry*, 17(4), 118-120.

Baron-Cohen, S. (2020). Understanding autism: The spectrum nature of the condition [Speech].Autism Research Centre, University of Cambridge.

Bashir, A., Bashir, U., Lone, A., & Ahmad, Z. (2014). Challenges faced by families of autistic children. *International journal of interdisciplinary research and innovations*, 2(1), 64-68.

Beauchesne, M. A., Kelley, B. R., &MeInyk, B. M. (2004). Evidence to support parental concerns as an early indicator of autism in children. *Pediatric nursing*, 30(1), 57.

# Psychological Experience of Parents of Children with Autism

Becker-Cottrill, B., McFarland, J., & Anderson, V. (2003). A model of positive behavioral support for individuals with autism and their families: The family focus process. *Focus on Autism and other developmental disabilities, 18*(2), 113-123.

Bitsika, V., & Sharpley, C. F. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. *Journal of Psychologists and Counsellors in Schools, 14*(2), 151-161.

Boswell, K., Zablotsky, B., & Smith, C. (2014). Predictors of autism enrollment in public school systems. *Exceptional children, 81*(1), 96-106.

Bozkurt, G., Uysal, G., & Düzkaaya, D. S. (2019). Examination of care burden and stress coping styles of parents of children with autism spectrum disorder. *Journal of pediatric nursing, 47*, 142-147.

Brown, H. K., Ouellette-Kuntz, H., Hunter, D., Kelley, E., Cobigo, V., & Lam, M. (2011). Beyond an autism diagnosis: Children's functional independence and parents' unmet needs. *Journal of autism and developmental disorders, 41*, 1291-1302.

Chiarotti, F., & Venerosi, A. (2020). Epidemiology of autism spectrum disorders: a review of worldwide prevalence estimates since 2014. *Brain sciences, 10*(5), 274.

Chiri, G., & Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and child health journal, 16*, 1081-1091.

Cohrs, A. C., & Leslie, D. L. (2017). Depression in parents of children diagnosed with autism spectrum disorder: A claims-based analysis. *Journal of autism and developmental disorders, 47*, 1416-1422.

# Psychological Experience of Parents of Children with Autism

Dababnah, S., & Bulson, K. (2015). "On the sidelines": Access to autism-related services in the West Bank. *Journal of autism and developmental disorders*, 45, 4124-4134.

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of autism and developmental disorders*, 38, 1278-1291

Demissie, M. (2015). Autism: Parents' experience and care practices in Addis Ababa (Doctoral dissertation, St. Mary's University)

Dempsey, I., & Dunst, C. J. (2004). The role of parents in the early intervention process for children with disabilities. *Journal of Applied Research in Intellectual Disabilities*

Dunlap, G., Iovannone, R., & Kincaid, D. (2008). Essential components for effective autism educational programs. *Effective practices for children with autism: Educational and behavioral support interventions that work*, 111-135.

Dunn, A. L., Trivedi, M. H., & O'Neal, H. A. (2001). Physical activity dose-response effects on outcomes of depression and anxiety. *Database of Abstracts of Reviews of Effects (DARE): Quality-assessed Reviews [Internet]*.

Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., ...& Yeargin-Allsopp, M. (2017). Autism spectrum disorder among US children (2002–2010): Socioeconomic, racial, and ethnic disparities. *American journal of public health*, 107(11), 1818-1826.

Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics*, 134(2), e454-e463.

# Psychological Experience of Parents of Children with Autism

Dymond, S. K., Gilson, C. L., & Myran, S. P. (2007). Services for children with autism spectrum disorders. *Journal of Disability Policy Studies, 18*(3), 133-147.

Elosúa, M. R. (2015). The influence of gratitude in physical, psychological, and spiritual well-being. *Journal of Spirituality in Mental Health, 17*(2), 110-118.

Eric, F. (2020). Epidemiological controversies in autism. *Swiss ArchivNeurol, Psychiatr Psychotherapy, 171*(1), 3-5.

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism, 13*(4), 375-387.

Feinberg, E., Augustyn, M., Fitzgerald, E., Sandler, J., Suarez, Z. F. C., Chen, N., ...& Silverstein, M. (2014). Improving maternal mental health after a child's diagnosis of autism spectrum disorder: results from a randomized clinical trial. *JAMA pediatrics, 168*(1), 40-46.

Fleischmann, A. (2005). The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism, 9*(3), 299-316.

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American psychologist, 55*(6), 647.

Fombonne, E. (2009). Epidemiology of autism spectrum disorders. *Pediatrics, 124*(4), 1045-1055

Gardner, D. G. (2020). The importance of being resilient: Psychological well-being, job autonomy, and self-esteem of organization managers. *Personality and Individual Differences, 155*, 109731.

# Psychological Experience of Parents of Children with Autism

Gebre, M. B. (2016). Resources in raising a child with autism in Ethiopia: Parents' Perspective (Master's thesis, The University of Bergen).

Hartley, S. L., & Schultz, H. M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of autism and developmental disorders, 45*, 1636-1648.

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of autism and developmental disorders, 31*, 327-336.

Imm, P., White, T., & Durkin, M. S. (2019). Assessment of racial and ethnic bias in autism spectrum disorder prevalence estimates from a US surveillance system. *Autism, 23*(8), 1927-1935.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical child and family psychology review, 15*, 247-277.

Kavaliotis, P. (2017). Investigation of the correlation of family resilience of parents with a child with autism spectrum disorders, parenting stress and social support. *International Journal of Psychological Studies, 9*(2), 1-15.

Kibreab, E. (2021). The Lived Experience of Mothers with an Autistic Child in Addis Ababa: A Phenomenological Study. *The Ethiopian Journal of Education, 41*(1), 223-246.

Koenig, H. G. (2012). Religion, spirituality, and health: The research and clinical implications. *International Scholarly Research Notices, 2012*(1), 278730.

## Psychological Experience of Parents of Children with Autism

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*, *122*(6), e1149-e1158.

Kuusikko-Gauffin, S., Pollock-Wurman, R., Mattila, M. L., Jussila, K., Ebeling, H., Pauls, D., & Moilanen, I. (2013). Social anxiety in parents of high-functioning children with autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, *43*, 521-529.

Lai, W. W., Goh, T. J., Oei, T. P., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of autism and developmental disorders*, *45*, 2582-2593.

Lajiness-O'Neill, R., & Menard, P. (2008). Brief report: an autistic spectrum subtype revealed through familial psychopathology coupled with cognition in ASD. *Journal of autism and developmental disorders*, *38*, 982-987.

Leigh, J. P., & Du, J. (2015). Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of autism and developmental disorders*, *45*, 4135-4139.

Lord, C., Elsabbagh, M., Baird, G., & Veenstra-Vanderweele, J. (2018). Autism spectrum disorder. *The lancet*, *392*(10146), 508-520.

Lucyshyn, J. M., Blumberg, E. R., & Kayser, A. T. (2000). Improving the quality of support to families of children with severe behavior problems in the first decade of the new millennium. *Journal of Positive Behavior Interventions*, *2*(2), 113-115.

## Psychological Experience of Parents of Children with Autism

McConachie, H., Randle, V., Hammal, D., & Le Couteur, A. (2005). A controlled trial of a training course for parents of children with suspected autism spectrum disorder. *The Journal of pediatrics*, *147*(3), 335-340.

Mackintosh, V. H., Goin-Kochel, R. P., & Myers, B. J. (2012). "What do you like/dislike about the treatments you're currently using?" A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *27*(1), 51-60.

Maenner, M. J. (2021). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2018. *MMWR. Surveillance Summaries*, *70*.

McStay, R., Trembath, D., & Dissanayake, C. (2015). Raising a child with autism: A developmental perspective on family adaptation. *Current Developmental Disorders Reports*, *2*(1), 65-83

Mesibov, G. B., Shea, V., & Schopler, E. (2005). *The TEACCH approach to autism spectrum disorders*. Springer Science & Business Media.

Montes, G., Halterman, J. S., & Magyar, C. I. (2009). Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics*, *124*(Supplement\_4), S407-S413.

Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and quality of life outcomes*, *5*, 1-9.

Murray, D. S., Fedele, A., Shui, A., & Coury, D. L. (2016). The autism speaks autism treatment network registry data: opportunities for investigators. *Pediatrics*, *137*(Supplement\_2), S72-S78.

# Psychological Experience of Parents of Children with Autism

Narzisi, A., Posada, M., Barbieri, F., Chericoni, N., Ciuffolini, D., Pinzino, M., ...&Muratori, F. (2020). Prevalence of Autism Spectrum Disorder in a large Italian catchment area: A school-based population study within the ASDEU project. *Epidemiology and psychiatric sciences*, 29, e5.

Nealy, C. E., O'Hare, L., Powers, J. D., &Swick, D. C. (2012). The impact of autism spectrum disorders on the family: A qualitative study of mothers' perspectives. *Journal of Family Social Work*, 15(3), 187-201.

Nevison, C. D., &Blaxill, M. (2017). Diagnostic substitution for intellectual disability: A flawed explanation for the rise in autism. *Journal of Autism and Developmental Disorders*, 47, 2733-2742.

Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated interventions for young children with autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders*, 43(4), 982-1020

Orlansky, M. D. (1988). Assessment of visually impaired infants and preschool children. In *Assessment of young developmentally disabled children* (pp. 93-107). Boston, MA: Springer US.

Papadopoulos, C., Lodder, A., Constantinou, G., &Randhawa, G. (2019). Systematic review of the relationship between autism stigma and informal caregiver mental health. *Journal of autism and developmental disorders*, 49, 1665-1685.

Qiu, S., Lu, Y., Li, Y., Shi, J., Cui, H., Gu, Y., ...&Qiao, Y. (2020). Prevalence of autism spectrum disorder in Asia: A systematic review and meta-analysis. *Psychiatry research*, 284, 112679.

## Psychological Experience of Parents of Children with Autism

Rice, C. E., Rosanoff, M., Dawson, G., Durkin, M. S., Croen, L. A., Singer, A., & Yeargin-Allsopp, M. (2012). Evaluating changes in the prevalence of the autism spectrum disorders (ASDs). *Public health reviews*, *34*, 1-22.

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical child psychology and psychiatry*, *17*(2), 229-245.

Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child & Family Behavior Therapy*, *19*(4), 15-32.

Samadi, S. A., McConkey, R., & Kelly, G. (2013). Enhancing parental well-being and coping through a family-centred short course for Iranian parents of children with an autism spectrum disorder. *Autism*, *17*(1), 27-43.

Schnabel, A., Youssef, G. J., Hallford, D. J., Hartley, E. J., McGillivray, J. A., Stewart, M., ... & Austin, D. W. (2020). Psychopathology in parents of children with autism spectrum disorder: A systematic review and meta-analysis of prevalence. *Autism*, *24*(1), 26-40.

Seltzer, M. M., Abbeduto, L., Krauss, M. W., Greenberg, J., & Swe, A. (2004). Comparison groups in autism family research: Down syndrome, fragile X syndrome, and schizophrenia. *Journal of autism and developmental disorders*, *34*, 41-48.

Shamsad, I. A. (2019). Autism spectrum disorder. *Bangladesh Journal of Medicine*, *30*(1), 1-3.

Side, A. S., & Kumar, R. S. (2022). Stressors and coping strategies among parents of children with autism spectrum disorder in Ethiopia. *Bahir Dar Journal of Education*, *22*(1), 76-96.

# Psychological Experience of Parents of Children with Autism

Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism, 6*(4), 397-409.

Smith, L. E., Seltzer, M. M., & Greenberg, J. S. (2012). Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 42*, 1836-1846.

Sun, X., Allison, C., Auyeung, B., Matthews, F. E., Baron-Cohen, S., & Brayne, C. (2013). Service provision for autism in mainland China: Preliminary mapping of service pathways. *Social Science & Medicine, 98*, 87-94.

Symon, J. B. (2001). Parent education for autism: Issues in providing services at a distance. *Journal of Positive Behavior Interventions, 3*(3), 160-174.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American psychologist, 38*(11), 1161.

Tekola, B., Baheretibeb, Y., Roth, I., Tilahun, D., Fekadu, A., Hanlon, C., & Hoekstra, R. (2016). Challenges and opportunities to improve autism services in low-income countries: lessons from a situational analysis in Ethiopia. *Global mental health, 3*, e21.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *BMC health services research, 16*, 1-12.

## Psychological Experience of Parents of Children with Autism

Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism, 18*(7), 815-826.

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative health research, 18*(8), 1075-1083.

Wills, S., Cabanlit, M., Bennett, J., Ashwood, P., Amaral, D., & Van De Water, J. (2007). Autoantibodies in autism spectrum disorders (ASD). *Annals of the New York Academy of Sciences, 1107*(1), 79-91.

Wright, B., & Williams, C. (2007). *Intervention and support for parents and carers of children and young people on the autism spectrum: A resource for trainers*. Jessica Kingsley Publishers.

Xu, G., Strathearn, L., Liu, B., & Bao, W. (2018). Prevalence of autism spectrum disorder among US children and adolescents, 2014-2016. *Jama, 319*(1), 81-82.

Zablotsky, B., Pringle, B. A., Colpe, L. J., Kogan, M. D., Rice, C., & Blumberg, S. J. (2015). Service and treatment use among children diagnosed with autism spectrum disorders. *Journal of Developmental & Behavioral Pediatrics, 36*(2), 98-105.

Zelege, W. A., Chitiyo, M., & Hughes, T. L. (2018). Autism service providers report: Behavioral and educational interventions used in Ethiopia. *International Journal of School & Educational Psychology, 6*(3), 176-187.

Zelege, W. A., Hughes, T., & Chitiyo, M. (2018). The path to an autism spectrum disorders diagnosis in Ethiopia: Parent perspective. *American Journal of Orthopsychiatry, 88*(3), 316.

# Psychological Experience of Parents of Children with Autism

Addis Ababa University

College of Education and Behavioral Studies

School of Psychology

## **ANNEX**

### **ENGLISH VERSION QUESTIONNER**

Date of Interview:

#### Introduction and Informed Consent

My name is \_\_\_\_\_; I am a graduate student in Addis Ababa University, School of Psychology .This questionnaire is prepared to gather information for a master’s thesis on psychological experience of parents with ASD child at St. Paul Hospital Millennium Medical Collage, Addis Ababa, for the partial fulfillment of requirements of Master’s Degree in counseling.

I kindly request your cooperation with providing your response to the written and verbal interview questionnaires. Notes will be taken during the verbal interview and if you feel comfortable, I will use an audio-tape to record the interview for the purpose of retaining complete information.

Please be aware that your participation in this project is voluntary, and you have the right to decline from your participation any time without penalty. You can contact the data collector if you have any questions concerning this study or your right as a research participant. Your identity and anonymity as a research participant in this study will remain secure.

Your active participation and genuine response is highly appreciated!

Participant Signature: \_\_\_\_\_ Date: \_\_\_\_\_

# Psychological Experience of Parents of Children with Autism

Data Collector Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix:-A

In-depth Interview Questions to the parents/caregivers of the autistic children

### I. Demographic Data

1. Gender: \_\_\_\_\_
2. Age: \_\_\_\_\_
3. Marital Status: \_\_\_\_\_
4. Relationship with the ASD child: \_\_\_\_\_
5. Education: \_\_\_\_\_
6. Age of the child: \_\_\_\_\_
7. Gender of the child: \_\_\_\_\_
8. Severity level of the child' autism: \_\_\_\_\_

### II. Psychological Experiences of Having a Child with Autism

1. What psychological problems do you face by having an autistic child? Can you describe how it affects your emotion or feeling, personal care and interaction with others?

Is there anything else?

2. How does the presence of ASD child in your family affect the family interaction, psychological wellbeing of other family member, marital relationship and family roles?

Probe-would you explain further

Is there anything else?

# Psychological Experience of Parents of Children with Autism

3. What challenges did you face as a consequence of your child's unusual behavior? (E.g. feeling as you're not able to socialize, having sense of isolation from the community, and/or be stressful).

Probe-would you explain further

Is there anything else?

4. What challenges do you experience when you take your autistic child out into the community? (E.g. people stare, make comments, and/or misunderstand your child's behavior)?

What did you feel at that time, or what actions have you taken as a result? How do you deal with the negative comments or misunderstandings?

Is there anything else?

## **III. Questions about coping mechanisms**

1. How do you deal with the challenges? What type of coping methods did you use as a solution? How does it help you to overcome the problems?

What do you think should be done at the community or government level to support parents of children with autism or what do you suggest to reduce the challenges of parents with autistic child?

Is there anything else?

## **IV. Questions about family and community support**

1. Do you have someone in your family to talk about your concern regarding your autistic child?

2. Have you ever tried to meet and talk with the other parents of autistic children in your community?

## **V. Service availability**

1. Do you have any support group to ease your psychosocial burden? If yes can you mention them? If no skip Q2,3 and 4.

## Psychological Experience of Parents of Children with Autism

2. Do you believe that those support groups play an important role to meet your needs?
3. Where do you find to be the most important source of support?
4. What kind of assistance or support do you get?
5. Did you get caregiver skill training at hospitals that you visited?
6. Did you get any psychological or emotional support from psychologist, psychiatrist and nurse professionals at hospitals that you visited?
7. Did you get any support from governmental and non-governmental bodies?
8. Do you think you get enough support and/or service from the health facilities?

# Psychological Experience of Parents of Children with Autism

## AMHARIC VERSION QUESTIONNER (አማርኛው ትርጉም)

የቃለ መጠይቁ ቀን:

መግቢያ እና በመረጃ የተደገፈ ስምምነት

የኔ ስም \_\_\_\_\_; በአዲስ አበባ ዩኒቨርሲቲ የስነልቦና ትምህርት ቤት ተመራቂ ተማሪ ነኝ። ይህ መጠይቅ “በቅዱስ ጳውሎስ ሆስፒታል ሜሊኒየም ሜዲካል ኮሌጅ ውስጥ በሚገኙ የኦቲዝም ተጠቂ ህጻናት ወላጆች ላይ የሚደርስ ስነ ልቦናዊ ጫና” በሚል ርዕስ የማስተር ተሲስ መረጃ ለመሰብሰብ ተዘጋጅቷል።

በፅሁፍ እና በቃል ቃለ መጠይቅ መጠይቆች ላይ ምላሽዎን በመስጠት ትብብርዎን በአክብሮት እጠይቃለሁ። በቃላት ቃለ መጠይቁ ወቅት ማስታወሻዎች ይወሰዳሉ እና ከተመቸዎት ሙሉ መረጃን ለማቆየት ቃለ-መጠይቁን ለመቅዳት የድምጽ-ቴፕ እጠቀማለሁ።

እባክዎ በዚህ ፕሮጀክት ውስጥ ያለዎት ተሳትፎ በፈቃደኝነት እንደሆነ እና በማንኛውም ጊዜ ያለ ምንም ቅጣት ከመሳተፍዎ የመቃወም መብት እንዳለዎት ይወቁ። ስለዚህ ጥናት ወይም የጥናት ተሳታፊ የመሆን መብትህን በሚመለከት ማንኛውም አይነት ጥያቄ ካሎት መረጃ ሰብሳቢውን ማነጋገር ትችላለህ። በዚህ ጥናት ውስጥ እንደ አንድ የጥናት ተሳታፊ ማንነትዎ እና ማንነትዎ አለመታወቅ ደህንነቱ የተጠበቀ ይሆናል።

የእርስዎ ንቁ ተሳትፎ እና እውነተኛ ምላሽ በጣም እናመሰግናለን!

የተሳታፊ ፊርማ:- \_\_\_\_\_ ቀን: \_\_\_\_\_

የደታ ሰብሳቢ ፊርማ:- \_\_\_\_\_ ቀን: \_\_\_\_\_

# Psychological Experience of Parents of Children with Autism

## Appendix:-B

ለወላጅ ወይም አሳዳጊ የሚቀርቡ ጥያቄዎች

### I. ስነ ህዝባዊ መረጃ

- 1- ጾታ: \_\_\_\_\_
- 2- እድሜ: \_\_\_\_\_
- 3- የጋብቻ ሁኔታ: \_\_\_\_\_
- 4- ከልጁ/ቷ ጋር ያለ ግንኙነት: \_\_\_\_\_
5. ትምህርት: \_\_\_\_\_
6. የልጁ ዕድሜ \_\_\_\_\_
7. የልጁ ጾታ \_\_\_\_\_
8. የልጁ ኦቲዝም ከባድነት ደረጃ \_\_\_\_\_

### II. የወላጆች ስነ ልቦናዊ ጫና

1. ልጅ የኦቲዝም ተጠቂ መሆኑ ስነ ልቦናዊ ጫና አሳድሮታል? እንዴት ስሜቶችን ፣ ለራሱን የሚሰጡትን የግል እንክብካቤ፣ ከሌሎች ሰዎች ጋር ያሉትን ግንኙነት ላይ እንዴት ተፅዕኖ እያሳደረ እንዳለ ሊገልፁልኝ ይችላሉ?

ተጨማሪ ነገር አለ ?

2. የኦቲስቲክ ተጠቂ ልጅ በቤት ውስጥ መኖሩ በተሰጠው ላይ ምን ዓይነት ተጽእኖ አምጥቷል? የኦቲዝም ልጅ በቤተሰብ ውስጥ መኖሩ በቤተሰብ መስተጋብር፣ የሌላው የቤተሰብ አባል የስነ-ልቦና ደህንነት፣ የጋብቻ ግንኙነት እና የቤተሰብ ሚናዎች ላይ ምን ተጽዕኖ ያሳድራል?

ተጨማሪ ነገር አለ ?

3. በልጆች ያልተለመደ ባህሪ ምክንያት ምን ችግሮች አጋጠሙት?

# Psychological Experience of Parents of Children with Autism

ተጨማሪ ነገር አለ ?

4. የኦቲዝም ልጅዎን ወደ ማህበረሰቡ ሲወስዱ ምን ምን ችግሮች አጋጠሙት?

ተጨማሪ ነገር አለ ?

### III. ተጽእኖዎችን መቋቋምን በተመለከተ

1. ያጋጠሙትን የተለያዩ ተጽእኖዎችን እንዴት ተቋቋሙ ? ምን ዓይነት የመቋቋሚያ ዘዴዎችን እንደ መፍትሄ ተጠቅመው ነበር? ችግሮቹን ለማሸነፍ የሚረዳዎት እንዴት ነው?

ኦቲዝም ያለባቸውን ወላጆች ለመደገፍ በማህበረሰብ ወይም በመንግስት ደረጃ ምን መደረግ አለበት ብለው ያስባሉ ወይም ኦቲዝም ያለባቸውን ወላጆች ተግዳሮቶችን ለመቀነስ ምን ይጠቁማሉ?

### IV. ቤተሰባዊ ና ማህበረሰባዊ ድጋፍን በተመለከተ

1. ቤተሰቦች ውስጥ ልጆችን በተመለከተ ስላሉት የልጆች የጤና ስጋት የሚያወራዎት ና በከባድ ሁኔታዎች ና ጊዜያት ላይ የሚያግዙት ሰው አለ ?

2. ሌላ የኦቲዝም ተጠቂ ልጆች ያሏቸው ቤተሰቦች ጋር ተገናኝተው አውረተው ያውቃሉ?

### V. አገልግሎትን እና ድጋፍን በተመለከተ

1. የእርስዎን የስነ-ልቦና-ማህበራዊ ሽክም ለማቃለል የድጋፍ ቡድን አለዎት? አዎ ከሆነ እነሱን መጥቀስ ይችላሉ

2. እነዚያ የድጋፍ ቡድኖች ፍላጎቶችዎን ለማሟላት ወሳኝ ሚና ይጫወታሉ ብለው ያምናሉ?

3. በጣም አስፈላጊው የድጋፍ ምንጭ ሆኖ ያገኙትው ከየት ነው?

4. ምን ዓይነት እርዳታ ወይም ድጋፍ አገኙ?

5. በጎበኛቸው ሆስፒታሎች የተንከባካቢ የክህሎት ስልጠና አግኝተዋል?

6. በጎበኛቸው ሆስፒታሎች ከሳይኮሎጂስት፣ ከሳይካትሪስት እና ከነርስ ባለሙያዎች ምን ዓይነት የስነ-ልቦና ወይም የስሜት ድጋፍ አግኝተዋል?

7. ከመንግሥታዊ እና መንግስታዊ ካልሆኑ አካላት ምን ዓይነት ድጋፍ አገኙ?

8. ከጤና ተቋማት በቂ ድጋፍ እና/ወይም አገልግሎት አገኛለው ብለው ያስባሉ?