Psychological Problems and Quality of Life in Primary Caregivers of Children with Autism Spectrum Disorder

Submitted by

Zuha Iftikhar

SP20-BPY-008

Supervised by

Ms. Bareera Saeed

DEPARTMENT OF HUMANITIES

COMSATS UNIVERSITY ISLAMABAD, LAHORE CAMPUS.

Psychological Problems and Quality of Life in Primary Caregivers of Children with Autism Spectrum Disorder

Zuha Iftikhar

SP20-BPY-008

Session (SP20-FA23)

BS Psychology

A Thesis Submitted in Partial Fulfillment for the Requirements of the
Degree of BS Psychology

DEPARTMENT OF HUMANITIES

COMSATS UNIVERSITY ISLAMABAD, LAHORE CAMPUS, LAHORE.

FALL 2023

Declaration

I, Ms. Zuha Iftikhar, Student ID: SP20-BPY-008, student of BS in Psychology, session 2020-2023, at this moment declare that the material printed in this thesis titled "**Psychological Problems and Quality of Life in Primary Caregivers of Children with Autism Spectrum Disorder"** is original work and has not been printed, published, or submitted as research work, thesis, or publication in any form in any university or research institution in Pakistan or abroad.

Dated: ___________________ Signature: ________________________

Dedication

With the name of Allah, the Most Gracious and the Most Merciful. My sincere gratefulness goes to my beloved parents, my esteemed supervisor, and my mentor for their endless support and encouragement.

Acknowledgments

In the name of Allah, the Creator of this universe who has authority and power over every living and non-living thing in the world. I am beyond grateful to Allah Almighty, the Al-Rehman and Al-Raheem who made me capable enough to write my dissertation.

The second most appreciable individual in completion of this thesis is my supervisor, Ms. Bareera Saeed who assisted me in every aspect of my research. She has been an ultimate support since the very beginning when the chosen topic was just an idea in my head. She made it all seem so doable that I found the direction of my thesis through her collaboration from topic selection to creating effective research questions. Her sense of commitment with her work kept me consistent throughout the project and helped me explore my interests more clearly.

I would love to express endless gratitude towards my parents, Iftikhar and Amina, who did not just believe in me in fact they did everything in their might to support me and my decisions. They helped me become a well-mannered and career-oriented individual who should be resilient and sturdy enough to go through the hardest circumstances on her own.

My friends have been an ultimate source of strength for me during the thesis work and even the whole university life. I would not have done it without their constant reminders of how I am worthy of achieving the heights of success if I work whole-heartedly. I am grateful to Shumaim Salman, Jaweria Afzal, Sania Raza, and Kamran Ahmad for always having my back in the past years. If they had not been here emotionally I would not have imagined to come this far.

My deepest gratitude goes to my mother's best friend Abida Sher, a resilient mother of an extraordinary autistic child, who inspired me to choose this topic for my final year thesis.

The instructors who provided me with resources and aided me in completing this research are equally appreciable. I would like to express my thanks to the people who have been here through thick and thin during my university life. Their kindness, capability, intellect, and endless support has helped me achieve my goal of completing this thesis. If it were not for all of the people who supported me, I might not have attained this much over these university years.

Zuha Iftikhar

Table of Contents

List of Tables

List of Figures

No. **Content** **Page #**

List of Appendices

Abstract

This study aims to assess how depression, stress, and anxiety levels of parents with Autistic children make an impact on their quality of life in Lahore. The research design for this study is correlational, and the sample consists of 120 parents (mothers and fathers). Participants were chosen using a purposive sampling technique. All parents were between the ages of 20 and 50 (Mean= 38.0, Standard Deviation=10.091). These parents were selected from four Autism centers in Lahore, Pakistan, respectively. In this study, various self-report measures were used to assess the study variables. These measures included a demographic questionnaire, the Depression Anxiety Stress-21 Scale (DASS-21), and the World Health Organization Quality of Life Questionnaire WHOQOL-BREF. A correlation study showed that caregivers with higher income levels had better Quality Of Life. In addition, there were significant correlations between DASS-21 and WHOQOL-BREF subscales. The correlation analysis suggested a significantly negative correlation between the Psychological Problems and Quality of Life variables. This means that when psychological issues worsen the Quality of Life of primary caregivers decreases. Dealing with the psychological challenges faced by caregivers of autistic kids, and how can their Quality of Life be preserved should be matters of concern. The results suggested that primary autistic caregivers need well-planned treatments and effective assistance.

Keywords: *psychological problems, quality of life, dass-21, whoqol-bref, autism spectrum disorder*

Chapter 1

Introduction

Pakistan's population is faced with a plethora of psychological problems stemming from the impact of the coronavirus. People with neurodevelopmental disabilities, including autism spectrum disorder (ASD), and their relatives can suffer an even greater blow (Constantino et al., 2020; Manning et al., 2020). It can be inferred that the benefits and harm of various forces, such as restricted educational opportunities for autistic children, narrow scope in terms of access to therapeutic services, a reduction in caring support, and disruption to daily activities will all have direct effects on the lives of ASD both children and parents (Kalb et al., 2021).

ASD is a neurological disorder that affects many of the world's children, yet it remains misunderstood. ASD victims also suffer in every aspect of life, including communication (or lack thereof), and their ability to interact with others and engage in behavioral activities. Of course, primary caregivers must deal with a host of emotional and practical problems that all impact the development lifestyle and well-being of their child. Looking after autistic people puts heavy psychological stress on people and is bound to influence all principal caregivers 'quality of life (Schnabel et al., 2019).

ASD is an umbrella term that encompasses a variety of neurodevelopmental disorders. All these disorders are characterized by impaired interpersonal and intra-psychological communications; and annular or stereotyped thinking activity (APA, 2013). ASD has been increasing worldwide, and so it is in Pakistan. There has been a sharp increase in the number of children with Autism Spectrum Disorder seen all over the country. The male-to-female ratio of 2.5:1 that means that for every 1 female, there are 2.5 males. So, the worldwide median is somewhere in the 1.8 to seven per 10,000 range (Chiarotti and Venerosi, 2020).

Several research studies show that parents of ASD children report greater stress than do those who have typically developing (TD) or other disabled children. Judging from the results of these surveys, mothers of autistic children have higher levels than average in terms of depression, anxiety, and stress. Their observations showed that ASD parents bear a heavier objective and subjective burden as compared to other types of families, have frequent psychological difficulties, and receive insufficient social support. In addition, a study by Picardi et al., (2018) compared mothers' and fathers 'experiences of caregiving burdens; it similarly concluded that the level of subjective burden is higher among moms than dads. Research from the Netherlands reveals that parents of children with Autism Spectrum Disorder (ASD) and Attention-Deficit Hyperactivity Syndrome (ADHD) are more likely to feel stressed when caring for their affected child than for a normal sibling. In addition, the parents had to endure a greater degree of stress than those in regular situations (Van Steijn et al., 2013).

Many studies find that parenting stress comes when demands exceed expectations, whether parents have high demands of themselves or are faced with the expectations of society (Holly et al., 2019). The multiple factors of parental evaluations, the environment, and the stress encountered in one's daily living have all contributed to increased parenting stress. It is like the tensions that parents feel within their marriage or at work and leads to negative parenting behavior and poor relations between parents and children (Holly et al., 2019).

For instance, Bhandari et al., (2020) argue that autism spectrum disorder involves the cumulative effects of epigenetic and developmental factors as well as environmental influences. The increase in the number of such cases has cast a light on how primary caregivers can make or break these children's lives, and whether worries about caring for an autistic child deplete their mental health and affect the way they live their own lives. It is necessary to figure out how does a diagnosis of autism spectrum disorder (ASD) affects the family as a whole. It typically results in altered family living habits and increased anxiety in parents; long-term, unresolved frustrations between husband and wife; and feelings of depression among the parents (Chan & Leung, 2020).

Parenting autistic people, and the management of children with autism spectrum disorder (ASD) is a particularly difficult job. They must attend to never-ending needs, make decisions about optimal therapies, deal with behavioral issues, and figure it all out. Primary caregivers of autistic children can quickly become exhausted by the stress, anxiety, and emotional burden of raising a child with ASD (Barker et al., 2011). This is more so for a country such as Pakistan, where societal expectations, cultural values and availability of resources can all influence caregivers.

The correlation between behavioral and emotional problems of children with ASD and parental anxiety and depression levels is strong (Machado et al., 2016). Mental stability is essential for caregivers to be able to provide the best possible support and assistance in caring for their autistic offspring and a child's mental health. The well-being and psychological state of a caregiver are intricately connected to that of the entire family and therefore have indelible connections to the development of a kid with Autism Spectrum Disorder (ASD). Thus, early diagnosis and timely treatment of depressed parents, especially mothers, is very significant to effectively deal with the negative health outcomes for both child and mother (Yu et al., 2016).

The purpose of this study is to explore the psychological difficulties faced by primary caregivers of autistic children in Pakistan and how these affect their overall quality of life. This research aims to further explore the relationship between quality of life and psychological well-being for parents having children with a chronic disorder like ASD. The problems faced by the caregivers of autistic children in Pakistan and the kind of impact they have on their quality of life will be this study's main objective.

ASD children put a lot of pressure on their parents and the people who care for them (Hayes & Watson, 2012). Many studies have demonstrated that parents of ASD kids suffer higher levels of stress from parenting (Cassidy et. al, 2008; Hoffman et al., 2009); comorbidities and aspects such as low levels of Intelligence Quotient (IQ), and Attention-Deficit-Hyperactivity Disorder (ADHD). Research suggests that children with lower levels of functioning require more help in everyday life (Peters-Scheffer et al., 2012; Simonoff et al., 2008).

It certainly is hard to raise a child with autism spectrum disorder (ASD) as it is very anxiety-producing. The cost of treatment for autism makes it difficult to get the correct diagnosis and inappropriate intervention; educational services are also often lacking (Ekas et al., 2010; Tomanik et al., 2004). Studies have shown that the long-term care of a disabled child creates stress in various aspects of parents 'and caregivers' lives. Among these are poor physical and mental health (Johnson et al., 2011; Peters-Scheffer et al., 2012); dysfunctions in the family environment (Rao & Beidel, 2009); and social withdrawal (Dunn et al., 2001). Research has also revealed that the caregiver often suffers bad side effects in terms of stress, anxiety, and depression (Bouma & Schweitzer 1990; Davis & Carter 2008).

Another important dimension is the physiological problems that develop in primary caregivers as a result of suffering from higher rates of stress, anxiety, depression, and other psychological ailments. The continuous pressures and problems inherent to caregiving cause caregiver fatigue, impaired mental health, and a lower standard of living. By researching what kind of problems caregivers face, we can also learn something about the psychological aspects of trouble they experience. Such knowledge can be used to find interventions and resources that help them achieve a better life's quality.

In the case of treating autistic children, for instance, there is increasing evidence that it is best to involve the entire family. It is like that because having caregivers personally implement interventions is beneficial for the child's learning. Thus, for example, the research of Kaslow et al., (2012) shows that when caregivers join in treatment interventions with children who suffer from ASDs they obtain better results than otherwise would be possible. In addition, the quality of life of those people who are caregiving, such as parents with whom these children live, needs to be looked at. This is because the caregiver must bear still more pain in carrying a child with disabilities (Raina et al., 2004). However, many studies have shown that the parents involved in raising children with ASD suffer from significantly greater depression, anxiety, stress, and emotional burden than caregivers of typically developing kids or those taking care of developmentally disabled or physically ailing autistic children (Montes & Halterman 2007; Estes et al. 2013; Hayes & Watson 2013). The other study closed thereby asserting that taking care of children with ASD makes people more frustrated and less able to properly look after their kids (Schieve et al., 2011).

From this study, psychologists or policymakers will have a better understanding of how to help parents and caregivers lessen their children's or patients 'distress. Besides the physical, continued distress among caregivers has also been associated with several psychological effects (Miodrag & Hodapp 2010; Razurel et al., 2013). According to Tomeny (2016), a report conducted on mothers of autistic children has shown that the correlation between ASD severity and maternal psychopathology is associated with caregiver stress. This means that as stress gets higher, there is often more psychological distress suffered by the mother.

ASD often involves the loss of facial expression, and impaired ability to interact socially. Therefore, they tend to be those who need the most support from caregivers (Bonis, 2016). The rates of disruptive and difficult children among ASD are higher than for patients with many other neurodevelopmental disorders (APA, 2013). These behaviors include unpredictable and disruptive actions like screaming for extended periods, violence or aggressive behavior, suicide attempts, and violent rages (McClintock & Hall, 2006). It is also frequently the hardest part of being a parent--dealing with children's behavioral problems. More difficult to deal with than problems of communication, or practical help for the child must be coping emotionally (Kissel and Nelson, 2016).

Since both are profoundly serious, it is important to take the time to know a bit about whether women who stay at home with ASD children feel psychologically burdened, because this directly influences the health of an entire family. The quality of care, the child's ability to meet everyday stressors, and life satisfaction all are related to caregivers 'emotional well-being.

This study aims to understand the psychological problems of autistic children's primary caregivers and how they affect quality of life. By examining how the caregivers feel and looking at the difficulties they face, we can get a glimpse of some aspects of psychological distress. With this research, we can discover which type of management and treatment is best for helping them live a richer life.

The focus of this investigation is on factors contributing to psychological problems among the main caregivers in one-child families with autistic children. Some factors are the severity of symptoms, and whether social networks can provide care or access to suitable services. For this purpose, a comprehensive study of existing literature will be made. In addition, this study intends to explore whether any relationships exist between the psychological impacts of caregiving and variables such as cultural background, socioeconomic status, or caregiver coping mechanisms.

Psychological Problems

A variety of symptoms are usually referred to as psychological problems, involving emotional or cognitive disturbances that impact different areas of one's life. The resulting symptoms are often lasting feelings of sadness, anxiety, agitation, increased stress levels, loss of focus, or even difficulty sleeping. Physical manifestations abound as well. It is clear that numerous factors, both biological and psychological as well as social, can lead to problems. Thankfully, there are multiple avenues for treatment, including psychotherapy, medications, and self-help strategies (National Institute of Mental Health, 2021).

A recent study has shown that most parents whose children are autistic spectrum disorder (ASD), particularly in comparison to those with Downs, cerebral palsy, or intellectual disability (ID) nondisabled neurotypical kids (Hayes and Watson, 2013). With stress as high as this it is natural to suggest that the parents of autistic children are more vulnerable than those with normal developing offspring, emotional psychiatry. Research has shown, however, that ASD children whose parents display an elevated level of psychopathology have difficulty fulfilling their obligations as parents to these children. They also experience more conflict with the child and confront far greater problems of behavioral control in the child than other autistic persons do. In addition, they could choose to adopt stricter disciplinary measures. Previous studies on parents of children with autism have focused on such issues as parental stress, quality of life, and social impact. However, there is a lack of any research at all on such psychological problems among these parents--let alone reviews and summary analyses.

The same survey has also found that Autism Spectrum Disorder (ASD) causes more stress for parents than Down's syndrome, cerebral palsy, and other forms of intellectual disability like Down’s. This quotation comes from the book by Hayes and Watson published in 2013. Given the higher levels of stress on parents, it would be understandable if they were more likely to suffer from psychiatric problems than those whose children had not been diagnosed as having Autism Spectrum Disorder. The study discovered that psychopathology is higher in parents of kids with Autism Spectrum Disorder (ASD) who have more severe symptoms. These types of families report a harder time fulfilling their parental roles, are at greater odds with the children, and suffer from behavior problems there as well. In addition, they will implement tougher punitive measures. Most previous studies of families with Autistic children spectrum Disorder (ASD) have focused on issues such as parental stress, quality of life, and social impacts. But at the same time, there is a lack of studies concerning these parents 'psychological distress done from a perspective of meta-analysis.

The degree of symptoms experienced by ASD sufferers, and the distress induced in those around them. Research has shown that these special children's caregivers are often distressed. The focus of research has quietly shifted to look for things that are related to and affected by ASD which can increase such people's distress--that is one line that future autism spectrum disorder research could follow. Numerous variables have been implicated in caregiver distress, including the severity of autism (Huang et al. 2014; Stuart and McGrew 2009). Child rigidity, ritualism, and stereotypic behavior have also been shown to be inversely proportional to caregiver stress levels. Problems with concentrated social or verbal communication are also marked by higher caregiver burden. This is supported by the studies of Davis and Carter (2008), and Lecavalier et al., (2006). But the results of these and earlier studies (Gilliam et al. 2001;

Rodrigue et al. 1985) also show that children with ASD are markedly below normal, let alone “other retarded ” kids who can do routine tasks for themselves without having to depend on others ’ help-emotionally blunted creatures they may be but at Research has revealed that there are indeed links between sources of caregiver stress and shortcomings in basic skills (e.g., Estes et al. 2013; Tomanik et al., 2004). Yet research also indicates that the degree to which a caregiver waters her or his petals does not appear to be significantly correlated with ASD symptomatology (Phetrasuwan and Shandor Miles, 2009). This is especially so if one considers general child behavior problems. With these conflicting results, further research must be done on this topic, and whether the relative severity of ASD symptoms affects the distress level of caregivers cannot yet be answered.

Behavioral and emotional problems often arise as direct consequences of autistic behavior. Thus, having ASD is itself one type of developmental problem that children may suffer from. It is a matter quite common with them indeed. Moreover, research by Ming et al., (2008) also provides evidence in support of this contention. Furthermore, he says that research shows the behavior problems of these children are a greater cause for distress in caregivers than ASD per se. However, Lecavalier et al., (2006) have provided evidence to support this possibility as well. Because discipline is an important means of rearing children, the problem of unruly behavior and temper tantrums causes one mother with autistic child major stress (Phetrasuwan and Shandor Miles, 2009).

The relationship between problematic behavior and caregiver distress deserves close attention. The level of distress among caregivers is usually in direct correlation with the degree of problem behavior by children. In the same vein, increased rates of such disruptive behavior typically result in greater levels of caregiver stress (Neece et al., 2012). Now that this relationship has been established, we should be looking to see if there are any variables involved in maintaining the connection. A study looking at the moderating variables that affect intervention effectiveness found higher levels of depression and stress to be linked with poorer treatment outcomes for children exhibiting externalizing behavior (Reyno & McGrath, 2006). When there is a problem with the behavior of children, it also must be examined whether protective factors can reduce caregiver distress.

Theoretical Perspective

Tripartite Model

The Tripartite Model of Emotions presented by Clark and Watson (1991) best explains psychological problems such as Depression, Anxiety, and Stress. What this model indicates is that both anxiety and depression are psychologically negative, while stress is a psychological reaction of feeling overburdened and being powerless to cope with burdens. According to Clark and Watson's model, negative affect consists of three main components-anxiety, depression, and stress (Clark and Watson, 1991). The three psychological problems as explained by Clark and Watson are given below:

Anxiety. This includes feeling physiological arousal, fearfulness, and autonomic responsiveness associated with the memory of impending threat or danger.

Depression. The term refers to low mood, sadness, and anhedonia (a loss of interest or pleasure) as well as feelings of worthlessness or a hopeless future.

Stress. Tension, irritability, and inability to face or pressures are all common symptoms of stress.

Quality of Life

“The World Health Organization defines individual quality of life as the way individuals perceive their position in life, in the context of the culture, value systems, expectations, goals, and standards that shape their lives (WHOQOL Group, 1998).”

The quality of life that one finds in a family depends on what it gives everyone, and how well the family creates its goals for society (Brown I., Neikrug S. & Brown R.I.) 2006). Parenting is indeed an exceptionally unique journey to be taken with children at your side in which you can give them love, and live a nurturing world For example, the birth of a child with disabilities or chronic sickness developing in an otherwise healthy person may change some family structures; it can impact daily schedules and living environments, thus affecting standard quality of life (Hohlfeld et al., 2018). Many parents of ASD children allude to a loss in general family quality of life felt from their child's arrival through most aspects of daily living.

Previous research in this area has utilized various indexes to measure quality of life (QOL) (Mugno et al., 2007; Shu and Lung, 2005). As an example, Mugno et al. (2007) found that parents of autistic children have a lower quality of life – much worse than parents with children with cerebral palsy or intellectual disability and even worse still compared to those whose development is usually normal). Researchers discovered that parents of autistic children had poorer scores in all these areas, including the degree to which their block moved about and interacted with others, general satisfaction in life as a whole, and even health. However, as noted earlier (see table), QOL more broadly encompasses all the numerous factors that affect living conditions and a particular person's sense of satisfaction with his or her own life. Not all things are easily targeted by healthcare interventions.

Previous studies in the field of Autism Spectrum Disorder (ASD) have primarily paid attention to examining adolescents with ASD and their parents who look after them. In most of these investigations, the main caregiver was the child's biological mother. Furthermore, very few studies have focused on the welfare of both mothers and fathers; reviews so far (Allik et al. 2006; Mugno et al. However, the research discovered that women's overall condition was more adversely affected than for fathers. In the therapeutic process, we find ongoing interactions and mutual stimulation between children and their caregivers (the parents). Caregivers can strengthen or weaken each other's effectiveness. They examined the quality of life for children with Autism Spectrum Disorder (ASD) and their primary caregivers, as well as how family relationships affect parenting. This study therefore researched the Health-Related Quality of Life (HRQOL) for both primary care and secondary care. A secondary caregiver is a phrase describing the person who, in the view of the primary caregiver, spends the second most time caring for their kid. For instance, the caregiver may be either one of the other parents or that parent's partner. Aside from examining overall physical condition, we also focused on the primary caregiver's quality of life to determine whether having a child with an Autism Spectrum Disorder (ASD) adversely affects the parent.

Theoretical Perspective

Bio-psycho-social Model

The bio-psycho-social model provides evidence for the concept of quality of life. This holistic view of health and disease, which integrates biological, psychological and social factors to achieve a complete understanding is called the Biopsychosocial Model. Dr. George Engel (1977) established this model to help compensate for the shortcomings of the previous biomedical model, which considered only biological factors related to health and disease.

Here's a breakdown of the components within the Biopsychosocial Model as it pertains to quality of life:

Biological Factors. The first of these involves one's physical condition, including hereditary factors and physiology as well as total health. With regard to quality of life, biological factors also could correlate with chronic illnesses and disabilities or physical limitations which may affect daily functioning capacity.

Psychological Factors. The mental and emotional aspects of one's life which include their thoughts, feelings, value concepts and ways to adapt are included in this component. An important psychological factor is how one feels about the quality of life. Psychological variables involved for the caregivers of autistic children could include stress, anxiety and depression levels as well as coping ability.

Social Factors. The social factors include the individual's relationships, support structures, community interaction situation and cultural atmosphere as well as socioeconomic status. Social relationships, access to support and the availability of resources in society can have a great impact on people's quality of life.

Environmental Factors. This encompasses the environments in which people reside, work and socialize. Living environment, medical care, social attitudes toward the disabled and community resources are all environmental factors that can influence an individual's physical well-being.

Applied to the environment of quality of life for caregivers in raising children with ASD. Biopsychosocial theory proposes that a person's overall sense of wellbeing comes from interactions between his or her own biology (for example, is the child healthy?), psychology (stress levels and coping ability), social network (such as support) plus environmental factors such as Knowledge of these various factors can inform measures to help and encourage the caregivers in this unique environment.

Population

This study focuses on the parents of autistic children. All caregivers (parents) of children diagnosed by a licensed practitioner as having Autism Spectrum Disorder can participate. The parents must be between the ages of 20 and 50.

Most children with ASD have problems related to social interaction and communication. Other problems include abnormal language development, impaired cognitive functioning (Park et al., 2016), strange and limited behavior as well as hostility, anxiety, or tantrums because of a failure to comply with external requests. Several studies have also highlighted the fact that it is extremely hard to control children with Autism Spectrum Disorder (ASD) (O'Nions, Happé, Evers et al., 2017). Al-Farsi et al. (2016) note that parents of autistic children frequently experience stress, despair, and anxiety as well. Why is it that only the mothers suffer, and what are the repercussions for family life and overall quality of life? Office manners also increase the possibility of personal stress (Sikora et al., 2013; Pisula & Porębowicz-Dörsmann, 2017). Research shows that mothers of autistic children are also equally liable to suffer anxiety and melancholy due to social discrimination (Öz, Yuksel & Nasiroglu 2019).

Association between Psychological Problems and Quality of Life

Professor Pan says that the child who suffers from a chronic illness such as autism or functional impairment, and for whom parents must assume the major burden of responsibility-layer goods Transportation problems are not unique to Taiwan The decisions taken by families concerning feeding are made on extremely limited information. But it has been noted that when someone like this gets stressed or experiences a sort of prolonged stress response. Various research studies have reported that parents of autistic children suffer from greater levels of depression and anxiety (Sairanen et al., 2019). Life with an autistic child brings forth a series of different challenges, ranging over family life on every level. There are practical needs and emotional pressures and may even become a big headache for the whole family. Tadesse, (2014) concludes that the diagnosis of autism is such an emotional blow to parents that it can impact their marriage, socioeconomic status, and even social interactions.

Most people do not realize just how demanding and difficult it can be to care for a child with autism. This is especially true the further along in the spectrum you go, past mild Autistic Spectrum Disorder (ASD) into severe ASD. A burden like this usually offers its share of psychological burdens, such as stress and anxiety, depression, or burnout. Studies have also indicated that relations between the definitions of caregivers- especially parents themselves, who take on this role early but do not normally suffer illnesses from their autistic child tend to involve elevated stress levels and are even connected with anxiety or depression (Allik et al., 2006; Eapen and Guan, 2016; Falk et al., 2014; Khanna et al.,2013). It is necessary to understand the condition of caregivers 'psychological health due to recognition that this could be one way to reduce harm emanating from the care being provided. One must seek out what helps people lead a high-quality life and beat down the negative effects on their mental state caused by doing useful work every minute. In addition, the research interpreting that work for Pakistan has never focused on another key issue such as the quality of life among primary caregivers. Studies on the psychological treatments of ASD have begun to be made.

Chapter II

Literature Review

The purpose of this chapter is to make a critical analysis of the current literature on quality-of-life research. Here, we explore further the relationship between psychological health and quality of life for primary caregivers of ASD children. The purpose is to systematize the currently available research to gain a better understanding of the psychological problems caregivers are confronted with in Pakistan. This literature review's purpose is to provide a clear understanding of how psychological problems, including stress, anxiety, and depression, that caregivers may experience affect their quality of life. It shows the relationship between filling in some of the people's information.

Research into the problems of primary caregivers at home has been quite exhaustive, covering everything from psychological issues to quality of life. Most children have Autism Spectrum Disorder (ASD). A comprehensive investigation of the full range of these effects still needs to be carried out before we can reach a firm conclusion as regards any general connection between psychological problems and caregivers 'quality of life.

Yet studies have shown that ASD mothers feel a lot of stress and burden (Mumtaz et al., 2022). Hence, the research population also included a group of mothers with autistic children (n = 84) to see how they assess their situation. Their kids are autists or have Autistic Spectrum Disorder (ASD). Study participants were asked to fill out a demographic questionnaire, Parental Stress Scale (PSS), and Zarit Burden Interview (ZBI). However, the statistic most telling of their burdens was that 53.6 % fell in moderate to severe brackets on both burden scales for showing a high degree of burden upon these women. In addition, the degree of autism and the medicine's effectiveness were strongly associated with mother stress. The results confirmed that mothers of children with ASD bear a heavy burden and stress. No variations were found according to the age of the children, severity level, or whether medication was being used.

Romero et al., (2021) conducted a cross-sectional study of the correlation between parent stress and psychological difficulties in parents with autistic kids, which investigates preschoolers. Measures were taken to evaluate the psychological distress of 70 parents with autistic children as a sample. In addition, this study examines the connection between parental distress and an increase in children's emotional problems. Indeed, numerous research projects have revealed that elevated levels of stress plus psychological unease in parents after their children are born tend to be strongly correlated with emotional and behavioral problems beginning from an exceedingly early age.

Kausar et al., (2019) studied the whole family to determine whether various socio-demographic variables could predict stress among parents of children with Autism Spectrum Disorder (ASD). Using stratified sampling, parents--both fathers and mothers-from different special education schools and centers in five Pakistani cities were selected to complete a questionnaire. Overall, 251 adults took part. The Parental Perceived Stress Scale was used to measure the degree of stress that parents were feeling. However neural networks indicate that parental education, monthly family income, severity of impairment, age of special child, and gender are the five prerequisites to feeling stress as a special child's Parent. The research showed that eliminating some of the sociodemographic stresses faced by families with an ASD child could reduce parental pressures.

Kalaivnai and Kalimo, (2018) conducted further research into the parents 'psychological difficulties in raising autistic children. He took a random sample of 50 participants, including fathers with autistic children (18) and mothers with autistic children (32). Samples used in the study were selected through simple random sampling methods. The data reveals that 32 percent scored less than 48 on the scale, indicating a low level of stress. Total 44 % of respondents scored between 48 and 57 points, indicating that they are only moderately stressed. Of the remainder, 24 % showed a score over 57. One can see that their stress level is considerable. But the score range demonstrates that because of their autistic child, moms, and dads were experiencing elevated levels of stress. The research also found that parents with a feeling of competence and confidence in their parenting skills can experience some reduction in stress under trying conditions.

Batool and Khurshid, (2015) carried out a cross-sectional field survey to explore the reasons why parents of autistic children feel stressed. The sample consisted of 100 parents (50 mothers and fathers each) whose children were autistic. At outdoor units of children's hospitals, institutions, and their residences the parents carried out assessments including childhood autism rating, sense of coherence), parenting self-efficacy (parental attribution for failure in childrearing), and motivational stress. There were close links among the levels of impairment, parenting stress, and parenting self-efficacy scores. This study showed that the seriousness of child impairment and parental self-efficacy were both indicators of levels of stress in parents. However, there was no trace of a relationship between parenting stress and demographic variables. They concluded that the severity of child impairment was by far the main factor in determining parenting stress.

Lai et al., (2015) conducted a study about the mental health and adaptive coping mechanisms of parents with autistic children. This study was designed to compare the psychological reported well-being of parents with typically developing children and those whose child had Autism Spectrum Disorder (ASD). A survey was conducted involving 73 parents of children with autistic spectrum disorders and 63 parents of normally developed children. Parents of children with autism spectrum disorders were found to have higher levels of parental stress, including self-perceptions and lifestyle issues such as lack of satisfaction in the relationship between parents and their child or dealing with bad kid behavior. In addition, the parents had a greater frequency of depressive symptoms and employed more active avoidance strategies than did mothers or fathers of children with normal development. No significant differences were found in the psychological condition and adjustment of parents whose children had ASD. Their study concluded that it is necessary to pay attention to the safety and basic needs of autistic children's parents.

To explore the prevalence of parental stress and psychological health among parents whose children have Autism Spectrum Disorder, a cross-sectional study was conducted on parents of autistic children (Nikmat et al., 2008). Among the 52 parents whose children were diagnosed as autistic, there were 34 females and 18 males. Ninety percent of respondents said they were under stress because of parenting, and 53.8 % presented clinical symptoms indicating psychological distress. The relationship between gender, occupation, and psychological well-being was meaningful. Many parents of autistic children feel great stress and psychological difficulties. I have emphasized that in dealing with the problems of autistic children, you cannot just look at one single element as being significant.

This research carried out by Lai, Gog, Oei, and Sung, (2015) investigated the psychological health of parents with autistic children. They also tried to explore how parents with children who die of Autism Spectrum Disorder (ASD) cope, and what their level of psychological well-being is. The survey included 73 parents of autistic children and 63 matched parents of typically developing kids. Results showed that the parents of ASD children had higher levels of parental stress (neighborhood conflict, negative self-perceptions, dissatisfaction with relationships with their child). Parents were also more likely to be burdened by problematic child behavior. Furthermore, these parents also had a higher rate of depression symptoms and were more likely to use passive avoidance coping strategies than the parents of normal children. Our research has found no major differences between parents of children suffering from ASD and their psychological well-being or coping ability. The results of the study also served to reinforce how important it is for parents with Autism Spectrum Disorder (ASD) children's emotional and adaptive needs to be taken seriously.

A further study showed that the behavioral issues faced by autistic children affect their mothers 'quality of life (Waheed et al., 2020). The sample consisted of 100 mothers and autistic children, divided into two equal groups Scales that rate the parental quality of life and Autism in children were used. The study's results reveal an impressive link between behavioral disorders in children with autism and the mothers of such children's quality of life. This study discovered that postgraduate mothers felt they did, indeed, enjoy a high quality of life. 50 % responded in the affirmative to this question. Furthermore, the study also found that children of postgraduate mothers had fewer autism-related behavioral problems. Based on a t-test, mothers who adopted the lifestyle of joint families had higher quality scores. Research into working mothers indicates there is a positive quality of life for working moms, and t-testing shows that the rate of autistic behavioral abnormalities among children born to performing parents was slightly lower than those without such work. In sum, this study revealed a negative relationship between autistic children's behavior problems and the quality of their mothers 'lives. A study comparing two different family systems, that of postgraduate working mothers with those undergraduates who stay at home gave the former higher status in terms of quality.

Alhazmi et al., (2018) compared the quality of life for locally based parents with children with autism spectrum disorder to that experienced by those responsible for typically developing kids in South Africa. It was a cross-sectional study of 52 parents 'quality of life. One-half of the parents had children who were on the autistic spectrum, and one had typical development. This assessment used a standard instrument, the World Health Organization Quality of Life Assessment-BREF. Of the 48 subjects in the ASD group, four were female. This is a gross overrepresentation of males in their number. Parental age was also about the same; in the ASD group, it had an average value of 32.9 (standard deviation = 7), and in the TD group, its mean was 37.8 years (SD = 6). The study findings revealed that parents of children with ASD had notably poorer mean scores in four domains of quality of life: They also discovered that parents of disabled children had a lower physical and psychological quality of life than the mothers and fathers of normal kids. The social and environmental environment was also inauspicious. In terms of the physical domain, there was a clear difference between those with ASD and normal development (ND) in many aspects. Retarded children not only face the problem of worse wages, but autistic children are also becoming worse and more severe as they grow older. These all have a major impact on the quality of life for these parents. More so given that these results point once again to parents of autistic children having a lower quality of life than those with typically developing (TD) kids. This is a general principle underlying all the objects being studied. This is a differentiation important to families and should be the priority of family management systems.

In a previous research study, Hsiao et al., (2017) studied the relationships between parental stress, family quality of life, and teacher-family partnership. They aimed to find ways that parents with autistic children could improve education by strengthening families. The study involved a questionnaire that was completed by 236 parents of school children with the disorder. Each variable was included in three assessment questionnaires. The relationships among these three variables were analyzed via structural equation modeling. Parental stress is immediately related to the happiness of one's quality of life. Similarly, the level of satisfaction felt by parents also directly affected their levels of stress. Exchanged capital The quality of family-teacher relationships affected the overall life quality for families, but they did not directly affect parental stress levels. Nonetheless, the effects of these family-teacher collaborations on parental stress were modulated by FQOL.

A study by Perumal, Veeraraghavan, and Lekhra, (2014) in India focused on the quality of life for parents with autistic children. The purpose of the study was to compare levels of quality-of-life (QOL) between parents with disabled children and a control group. In addition, the study tried to explore parental QOL based on differences in the severity of their child's disease. Our sample comprised 140 parents, including 73 mothers and fathers. Participants were evaluated using the Indian Scale for Assessment of Autism, while their quality of life was measured with a WHOQOL-BREF questionnaire. The method was used to determine the difference in quality of life between various groups. Hence, the quality of life for parents of autistic children is below that in all four areas measured by WHOQOL-BREF relative to both neurotypical and physically disabled youngsters. In sum, the survey showed that regardless of which domain (the social aspect has four subdomains- Physical, Psychological, Social, and Environmental) under WHOQOL-BREF is used to measure well-being in life), overall family quality of life dropped noticeably among parents with autistic children.

Therefore, these studies give a comprehensive examination of the literature which shows that such psychological problems do indeed impact all, especially autistic children's primary caregivers. Thus, their primary caregivers are psychologically impaired and have an inferior quality of life.

Rationale of the study

Caring for a child with Autism Spectrum Disorder (ASD) is exceedingly difficult and tiring, research studies carried out in various nations have found. Because of this, primary caregivers often suffer from psychological problems including stress and anxiety, sadness, or even overwhelming exhaustion. Studies have also shown that parents, especially mothers of autistic children, are more prone to physical illness and mental problems such as elevated levels of stress or anxiety (Allik et al. 2006). This is mainly because caring for autistic children brings stress and difficulties. Second, we must find out which variables can enhance the caregivers 'quality of life or reduce the negative effects that caregiving exerts on the mental health of the primary caregivers. This is why we are concerned with the psychological problems of caregivers. Moreover, little research has been done in Pakistan regarding the quality of life in primary caregivers of children with Autism Spectrum Disorder. It is thus important to conduct research on assessing the psychological problems in caregivers of children with Autism Spectrum Disorder as well as comprehending the impact of these negative outcomes on their quality of life.

Objectives

The key objectives of the study include:

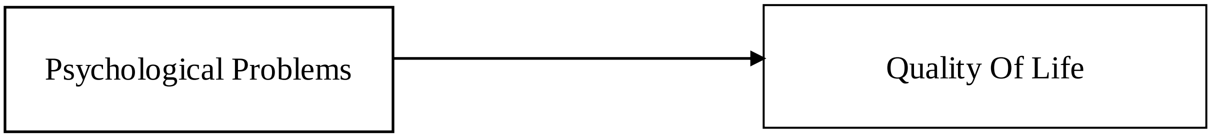
- To determine the prevalence and severity of psychological problems, such as anxiety and depression, among primary caregivers of children with Autism Spectrum Disorder.
- To assess the relationship among family income, psychological problems, and quality of life in parents of Autistic Children.
- To investigate the impact of psychological problems on the quality of life of primary caregivers of children with Autism Spectrum Disorder.

Hypothesis

The following are the hypotheses of the study:

- There is likely to be a significant correlation among family income, psychological problems, and quality of life among parents of children with ASD.
- There is likely to be a significant correlation among psychological problems, quality of life, and their subscales in parents of Autistic children.
- There is likely to be a significant negative correlation between psychological problems and quality of life in parents of children with ASD.

Hypothetical Model



Chapter III

Method

The contents of this chapter encompass the research design, sample selection and sampling technique, assessment measures, process, and ethical considerations.

3.1. Research Design

The present study employed a Correlational research design. The purpose of this study was to investigate the correlation between psychological issues and the overall quality of life of parents who have children diagnosed with Autism Spectrum Disorder.

3.2. Sample

The study's sample consisted of 120 parents of children with autism (N = 120), with 53 mothers and 67 fathers. The ages of the parents ranged from 20 to 50 years, with an average age of 38.0 and a standard deviation of 10.091. A purposive sampling technique was used to collect the data from Springfield Autism Centre, Step Ahead Autism Centre, Step Above Autism Centre, and Autism Resource Centre in Lahore, Pakistan.

3.2.1. Inclusion criteria

1. Participants must be primary caregivers (parents) of children with Autism Spectrum Disorder, diagnosed by a licensed healthcare provider.

2. Participants must be 20 to 50 years of age.

3. Participants must be educated enough to understand the questionnaire.

3.2.2. Exclusion criteria

1. Participants who have a history of severe mental (e.g., schizophrenia, bipolar disorder), physical illness, or substance abuse may be excluded, as they may impact their ability to respond accurately.

2. Participants who have been primary caregivers for less than six months may be excluded, as they may not have had sufficient time to develop an in-depth understanding of the difficulties faced by parents having autistic kids and the negative effect of caregiving children with ASD.

3.3 Operational Definition of Variables

Following are the operational definitions of the study variables.

3.3.1 Psychological Problems. Psychological problems refer to a range of symptoms that can hinder individuals' ability to function in various aspects of their lives, including socially and occupationally. Symptoms may include a general sense of depression, anxiety, agitation, pressure, and stress; trouble concentrating or sleeping; and physical problems. There are a variety of factors that may cause psychological problems, including biological, social, and psychological levels. All these problems can be treated, whether through psychiatric treatment, medication, or self-help (National Institute of Mental Health 2021).

3.3.2 Quality of Life. The definition of Quality of life as given by the World Health Organization states that “It is an individual's subjective assessment of one's personal life circumstances, based on person (cultural and societal), expectations, aspirations, and worries.” So, we must focus on whether a condition is present or not and also assess its overall impact and experience. The WHO's definition of health stresses the complete experience of the individuals. This integrated method can help us get a better idea of an individual's quality of life. Kelley-Gillespie, (2009) states that factors affecting the quality of life are divided into social, physical, psychological spiritual cognitive, and environmental dimensions.

3.4. Assessment measures

The assessment tools that were used in the present study are as follows:

1. Demographic Sheet

2. Depression, Anxiety, Stress Scale (DASS-21)

3. World Health Organization Brief Quality of Life Scale (WHO BREF-QOL)

3.4.1. ***Demographic sheet.*** The study included a demographic information sheet that collected data on numerous factors. These factors included the parent's age, the child's age, the gender of both parents, the type of family system (nuclear or joint), the number of siblings including the child, the birth order of the child, the area of residence (rural or urban), the parent's employment status (full-time employed, part-time employed, self-employed, unemployed), the educational background of the parent (educated or uneducated), and the completed levels of education if the parent is educated.

3.4.2. ***Depression, Anxiety, Stress Scale (DASS-21).*** The Depression, Anxiety, Stress Scale (DASS-21) is a measurement tool used to assess levels of depression, anxiety, and stress. The primary objective of the Depression Anxiety Stress Scales-42 (DASS-42), created by Lovibond and Lovibond (1995), is to accurately distinguish between self-reported anxiety and depression by thoroughly assessing the fundamental symptoms associated with both conditions. Antony, Bieling, Cox, Enns, and Swinson, (1998) subsequently verified that both the initial DASS-42 and a condensed version, the DASS-21, successfully distinguish between aspects of depression, physical arousal (anxiety), and psychological tension (stress) in both clinical and nonclinical populations. Research has shown that the DASS-21 possesses good internal consistency reliability (Cronbach’s alpha ranged between 0.74 and 0.93) in both clinical and non-clinical samples (Ali & Green, 2019). As to the Psychology Foundation of Australia (2011), the DASS is not intended for diagnostic use. Conversely, the three subscales of the scale (depression subscale, anxiety subscale, stress subscale) assess distinct dimensions of anxiety and depressive disorders quantitatively. The DASS-21 is a questionnaire that individuals complete themselves, which has 21 items. The objective is to evaluate the prevalence of depression, stress, and anxiety among the population. The scale comprises seven items, each offering four response alternatives. The available choices span from 0 (completely applicable to me) to 3 (very applicable to me, occurring frequently or most of the time). If an individual achieves a score of 42 on each scale, it indicates the possibility of heightened levels of depression, anxiety, or stress. The scores are multiplied by a factor of 2 to maintain comparability with the DASS-42. The DASS-21 total scale score has good internal consistency, as reported by Henry and Crawford, 2005. In addition, the score interpretations of the test are backed by convincing evidence of its construct validity (Henry & Crawford, 2005; Page, Hooke, & Morrison, 2007). The three DASS scales comprise 14 items apiece, which are subsequently subdivided into subscales of 2-5 items that exhibit comparable content.

The Depression scale assesses multiple facets of mood, perspective on life, self-esteem, involvement, pleasure, and drive. The Anxiety scale assesses different dimensions associated with anxiety, such as physiological arousal, muscular effects, situational anxiety, and the subjective perception of anxious emotions. The Stress scale precisely assesses levels of chronic non-specific arousal. The examination evaluates variables such as the level of challenge in achieving relaxation, the degree of nervous arousal, and a propensity to readily experience feelings of being upset, irritated, irritable, overreactive, and impatient. Participants are instructed to evaluate the magnitude of their experiences using 4-point severity/frequency ratings within the past week. The scores for Depression, Anxiety, and Stress are calculated by summing the scores for the respective items.

3.4.3. *World Health Organization- Quality of Life BREF Scale (WHOQOL-BREF).*

The WHOQOL-BREF is a self-administered questionnaire created by the World Health

Organization. It is a condensed version of the WHOQOL-100. The examination has 26 items categorized into four primary domains: physical health, psychological health, social relationships, and environmental health. The items are assessed via a 5-point rating system. If individuals possess adequate reading proficiency, it is advisable for them to independently administer the WHOQOL-100 questionnaire. Nevertheless, if they do not, it is recommended to utilize interviewer-assisted or interviewer-administered forms. The Cronbach's Alpha coefficient for the physical health subscale is 0.82. The psychological subscale demonstrates a prominent level of internal consistency, as shown by a Cronbach's alpha value of 0.75. The social interactions subscale has a Cronbach's alpha coefficient of 0.66, while the environmental subscale has a Cronbach's alpha coefficient of 0.80. These values indicate an elevated level of internal consistency according to the World Health Organization (WHO, 1998).

3.5. Procedure

Research began systematically by seeking permission from the scales authors’ to use them in data collection. The researcher contacted the Department of Humanities for official authorization letters, which were then sent to each center's director. The parents were formally asked to give consent before the scales defined above were administered, and they were assured that their response was strictly confidential. He reminded the participants that they had a right to withdraw from the study at any time. The researcher then proceeded to describe the importance of his work and the nature of tools. They were then asked to sit down comfortably and fill out the questionnaire. Each participant was given a clear explanation and understanding of the goals of such research, which concerned family members serving as primary caregivers for autistic children. About 15 or 20 minutes were needed for each set of questionnaires. The researcher visited Springfield Autism Center, Step Above Autism Center, Step Ahead Autism Center, and

Autism Resource Center for data collection. There were specific timings for the children having Autism, so the researcher visited only during those hours to collect data from the parents. After receiving guidance from the researcher, most parents were comfortable completing the form after thoroughly reading the questions and answering them accordingly. However, some disagreed to participate, and their choice was respected. The researcher gave enough space to the participants to minimize any bias in their responses.

Overall, the researcher gave 150 copies to the different autism centers and 120 were returned. After multiple visits for data collection from those centers, the researcher conveyed gratitude notes to the parents who participated in the study, and for effective cooperation, the researcher also thanked the authorities. The data was also collected in the same way from other centers. After completion of data collection results were analyzed. Response rate was 80%.

3.6. Ethical Considerations

The research was conducted with a strong focus on ethical considerations.

- The authors obtained permission from the authors of the assessment scales utilized in the current research.
- Permissions were obtained from the relevant authorities of the data collection centers.
- The participants were provided with written consent, informing them of the research's purpose and their right to withdraw at any time.
- The anonymity of participants was carefully preserved, and the confidentiality of data was rigorously upheld.
- The results were accurately reported.

Chapter IV

Results

Research has been done to study the correlation between psychological problems and quality of life in parents with Autism Spectrum Disorder ASD children. Data analysis was conducted with the assistance of version 25 of SPSS. The second phase of analysis was a look at the descriptive statistics for demographics and study variables. The second step involved the calculation of Cronbach's Alpha values to test for the internal consistency of the scales employed in this study. In addition, Pearson Product Correlation was performed to determine correlations between demographics and study variables. Next, correlations among the study variables and subscales were made.

Table 1

Descriptive Statistics of the Demographic Characteristics of the Sample (N=120)

Variables	*M*	*SD*	*f*	%
Age of Parent	38.0	10.091		
Age of Child	10.27	7.437		
Gender				
Father			67	55.8
Mother			53	44.2
Family System				
Nuclear			67	55.8
Joint			53	44.2
Birth Order of Child	2.66	1.590		

No. of Siblings	2.48	1.296		
Area of Residence				
Rural			37	30.8
Urban			83	69.2
Family Income	274833.33	149913.04		
Employment Status				
Full-Time Employed			31	25.8
Part-time			26	21.7
Self-Employed			35	29.2
Unemployed			28	23.3
Completed Levels of Education				
Matric			14	11.7
Intermediate			26	21.7
Graduate			35	29.2
Post-graduate			45	37.5

Note. For gender; 1= Father and 2= Mother; For family structure; 1= Nuclear and 2= Joint; Area of Residence; 1= Rural, and 2= Urban; For employment status; 1= Full time Employed 2= Part-time employed, 3= Self-employed and 4=Unemployed, and 5=Widowed; Educational Background; 1=Educated, and 2=Uneducated; Completed Level of Education; 1=Matric, 2=Intermediate, 3=Graduate, and 4=Post-graduate

Table 1 presents descriptive statistics for the demographic variables in the analysis. Continuous variables were expressed in mean and standard deviation. However, the categorical variables were presented in terms of percentage and frequency.

The descriptive statistics and Cronbach's Alpha values of the items in the scale are shown in Table 2.

Table 2

Reliability Analysis of Study Variables. (N=120)

Study variables	K	α	M	SD	Range
Psychological Problems	21	0.878	17.4833	9.99662	4-43
Quality of Life	26	0.867	83.9833	10.82868	47-103

Note. K= No. of items, M = Mean, SD = Standard Deviation, α = Cronbach's Alpha

Cronbach's Alpha scores in theory should produce a number between 0 and 1. The higher the Cronbach's Alpha, the greater the internal consistency of items on a scale. The scales used in the study had good reliability (over 0.6 on both).

It was hypothesized that there is likely to be a significant correlation between family income, psychological problems, and quality of life among the parents of children with Autism Spectrum Disorders. Pearson Product correlation was used to determine whether there is any relationship between family income, Psychological Problems, and Quality of Life. Intercorrelations of demographics and study variables are presented in Table 3.

Table 3

Inter-Correlations of Demographics and Study Variables (N=120)

Study Variables	1	2	3
1. Family Income	_	-.014	.316**
2. Psychological Problems		_	-.252**
3. Quality of Life			_

Note. $^{*}p<.05$, $^{**}p<.01$

According to Table 3, there is a moderate positive correlation between family income and the quality of life for caregivers in the sample. This seemed to indicate that the higher family income people had, the better quality of life they experienced.

We assumed that there was a good relationship between psychological problems, quality of life, and their subscales for the main caregivers of ASD children. The correlations between the study variables and their sub-scales are presented in Table 4.

Table 4

Correlation of Study Variables and Subscales (N=120)

	1	2	3	4	5	6	7	8	9
1. Psychological Problems	_	.906**	.903**	.881**	-.252**	-.184*	-.159	-.260**	-.241**
2. Depression		_	.759**	.687**	-.235**	-.166	-.117	-.272**	-.240**
3. Anxiety			_	.673**	-.181*	-.098	-.089	-.215*	-.206*
4. Stress				_	-.259**	-.228*	-.218*	-.212*	-.202*
5. Quality of Life					_	.789**	.846**	.742**	.881**
6. Physical Health						_	.570**	.486**	.539**
7.PsychologicalHealth							_	.520**	.643**
8. Social Relationships								_	.601**
9. Environment									_

Note. $^{*}p<.05$, $^{**}p<.01$

According to the table, there is a high degree of correlation between psychological problems and the Quality-of-life scale as well as with each subscale. Hence, the hypothesis was approved.

It was hypothesized that there exists a negative correlation between psychological problems and quality of life among the primary caregivers of ASD children. It further suggests that caregivers of patients with better quality of life reported fewer psychological problems.

Table 5

Correlation of Study Variables (N=120)

Study Variables	1	2
1. Psychological Problems	_	-.252**
2. Quality of Life		_

Note. $^{*}p$<.05, $^{**}p$<.01

Given table revealed that the presence of psychological problems among the parents of autistic children has a negative correlation with their quality of life. Hence, the hypothesis was approved.

Summary of Results

The result of the correlation analysis showed a moderate positive correlation between quality of life and family income. In other words, the higher the income of parents with ASD children, the lower their level of reported psychological problems.

In addition, a correlation of the study variables also revealed that there is a negative relationship between psychological problems and quality of life. This indicates that the higher the levels of psychological problems, the lower were those of quality of life for these caregivers with ASD children.

Chapter V

Discussion

This study was concerned with the link between psychological disorders and quality of life for primary caregivers of autistic children. They speculated that there is a relationship between family income and psychological problems caused by the caregiver, as well as their quality of life. What is more, correlations among the subscales of psychological problems and quality of life (depression, anxiety, stress; physical health recalling if experiencing a variety of illnesses; feeling well psychologically recalling whether suffering from feelings such as depression or tension) were all extraordinarily strong. The research shows there to be a negative correlation between ASD psychological problems and the quality of life of primary caregivers. The focus of this research is on the unique obstacles faced by primary caregivers for children with ASD, and how their psychological problems adversely impact every aspect of life. The findings are to the results of previous research (Patel et. al, 2022), which shows that low family income leads to higher levels of psychological illness among caregivers and increased likelihood ailments will worsen over time, adversely impacting the quality of life for those providing long-term informal home care support. Moreover, some of these variables had been studied previously.

The first hypothesis was that children with autism spectrum disorder (ASD) typically had parents whose psychological problems were connected to family income failure. This study also suggested a clear link between family income and quality of life as well as psychological problems among these parents. Worth noting is that those caregivers with a higher family income have fewer psychological problems and feel they are living better. The results reveal a negative correlation between family resources and psychological problems, suggesting that as income rises levels of stress, anxiety, or depression decline. In contrast, parents in the lower socioeconomic strata recorded an increase in psychological problems. It was their goal to be consistent with studies showing a correlation between financial hardship and increased ASD caregivers 'psychological distress.

What is more, the correlation analysis indicated a significantly positive relationship between parents 'estimates of quality of life and family income. Overall quality of life scores were high for those with higher family incomes. There is a relationship between caregivers 'economic security and resources, on the one hand, and their level of well-being (including quality of life), on the other. Mohamad Aun et al., (2021) also pinpointed which aspects of quality of life were most troublesome for mothers caring for children with high-functioning autism. According to his research, a stable monthly income can reduce the emotional burden that mothers feel when caring for autistic children. Material welfare also involves transportation, medical care, and a sense of safety in society. However, there is a clear link between family income and psychological problems. There are certainly alternative influences on the mental health of caregivers that have a bearing on quality of life. The results also show how complex the relationship is between socioeconomic status, psychological health, and quality of life for parents who are caring for autistic children.

Regarding family culture, Papadopoulos et al., (2023) recently examined the influence of mothers’ demographic characteristics and parents' stress levels along with children’s coping strategies, their illness perceptions, and quality of life in families whose members had Autism Spectrum Disorder on each other. For instance, the study showed strong correlations between monthly family income, marital status, total FQoL score, and some of its specific domains. However, there has been little research into these two aspects of FQoL in the brief time that follows diagnosis. In addition, sufficient resources like recreational activities, medical treatment, and transport are necessary if one is to enjoy more comfortable living conditions. Many parents only accept money for living expenses. Having an ASD child is both a financial burden on the family and can affect home life. Further, higher-income families are better able to bear the added burdens of health care and daily living for members with disabilities. These findings were in accord with the study's conclusion that there is a strong correlation between family income, psychological distress, and quality of life.

In a study, Naheed et al., (2020) investigated how much major depressive disorder affects the lives of mothers whose children had ASDs. Based on their findings, quality of life was correlated to factors such as MDD among the mothers and dissatisfaction with healthcare for autistic children. Their neighbors 'attitudes hurt their kids, and the stigma burnt off. QoL was also positively correlated with respondents 'reported family monthly incomes. In addition, the performance of children with ASD attending school also improved.

It also seems noteworthy that in earlier research, income was always related to physical health-the higher your income the better. This confirms Bromley, Hare, Davison, and Emerson's (2004) study which found that families with greater assets were less disturbed by the prospect of having children who have ASD. Also, according to Pakenham et al. (2005), mothers who were older and of higher socio-economic status had less anxiety about their children's HFASDS than those at lower levels across the board. Income can also allow parents to better support their kids and give them a respite from the tasks of parenthood.

The second hypothesis of the study was that psychological problems showed a high correlation with quality of life and its subscales (depression, anxiety, stress, physical health statuses). Q. Inter-correlations among various psychological measures were also investigated by

Park et al., (2019) for their predictive validity about distress, QoL, disability, and work loss days. They found strong correlations in measures of depression, anxiety, and stress.

Correlations between these symptoms and psychological distress were only moderately high. As expected, the correlations between anxiety and stress and quality of life were much lower than with depression. The strength of the correlation was higher than those for depression and anxiety, with most able to show prominent levels. The study also discovered a positive correlation between depression, anxiety, and distress, on the one hand; and workdays lost per month on the other. Multiple regression analysis, adjusting for age and gender as covariates revealed that distress was related to depression, anxiety, and stress. Most measures of quality of life and work loss days were highly correlated with depression, but the exceptions included overall quality of life, social quality of life, and environmental s. The quality-of-life environment here also was affected by gender and depression. Furthermore, gender and stress served as predictors for overall disability and participation. Stress alone predicted cognitive impairment effectively. The follow-up study investigates which kinds of psychological impact depression, anxiety, and stress have on sufferers.

The third hypothesis of the research was that there is a negative correlation between psychological problems and quality of life among primary care providers for autistic children. The study's results also offer evidence for the relationship between psychological distress and quality of life, showing that primary caregivers (parents with children who have ASD) see negative consequences. In a study into the life of mothers raising children with ASD, Predescu, and Sipos (2013) looked at whether there is any correlation between coping styles, emotional distress levels, and quality of life. Family quality of life is correlated with parents' negative emotions. They found that scores for negative dysfunctional emotion and sadness or depression identified these as two main factors behind poor family quality of life. Another study of a similar nature by Karaivazoglou et al., (2019) attempted to quantify anxiety, depression, and quality of life among parents with children having developmental disabilities. The results also fit in with those of the current study. Researchers responded that raising a child with any developmental disorder, including ASD, is intricately linked to serious psychological issues such as anxiety and depression. The study also revealed lower levels of quality of life.

Conclusion

In sum, the study also tended to affirm that high income translated into a higher quality of life and less severe forms of psychological illness. The many-sided interactions among variables that have been revealed help us understand what sort of coordinated action must be taken to solve people's problems with taking care of autistic kids. The study revealed that the psychological problems and four aspects (physical, psychological, social relations, and environment) of quality of life had a close relationship. Only that such proof of relationships between certain aspects with distinct levels of quality only underlines how this is a complex relationship.

Overall, this study shows that the quality of life for primary caregivers in ASD families has a significant negative correlation with psychological problems. Thus, it seems to say that as parental psychological problems increase in number neither does quality of life improve. Similar effective evidence for the hypothesis points out that if psychological problems can be treated in those who look after ASD children, then their quality of life will improve.

Limitations

- As the research was not carried out throughout Pakistan, it may not apply to people in wider regions of Pakistan.

- The research was conducted on many adults with a wide range of co-morbid problems (e.g., learning difficulties, ADHD, or some medical condition). If this information is not mentioned, it may lead to a misunderstanding of autism's natural state and major subjects are excluded.
- The sample was taken from centers for children with autism, so it is possible that the parents of ASD kids in the general population were hardly represented.
- Because it was a preliminary study, the number of participants in this sample test may not have been large enough to allow accurate statistical analysis.

Suggestions

- A greater number of areas need to collaborate with multiple autism centers for this research to be carried out on caregivers of children with ASD. This more comprehensive approach will help in understanding the experiences of caregivers around the world, as well as better appreciating their challenges and difficulties.
- It would be appreciated to see a more comprehensive range of variables affecting parental stress and quality of life. This might include negative life events and exposures; family issues; financial difficulties; or comorbid conditions such as epilepsy that are commonly seen in people with ASD. Exploring these facets has helped to better understand how they impact caregivers 'levels of stress and quality of life.
- A larger sample size and greater depth in the selection of subjects would make future research more valid. In this way, many of the complex factors affecting parental stress and well-being can be examined in depth.
- Carrying out qualitative research can help assess the underlying psychological problems and the risk factors associated with having a child with ASD.

- Longitudinal research can also be effective in monitoring changes in caregivers 'stress levels and well-being over time. Longitudinal studies help us to understand the continually evolving challenges faced by caregivers and the negative health-related outcomes of caring for a child with ASD.
- Establishing programs or other support services that meet the specific needs of mothers (in particular) would be even better. These programs could supply counseling, educational materials, and community assistance to reduce caregivers 'stress levels in addition to enhancing their quality of life.
- To enable the combined efforts of researchers, healthcare providers, and policymakers to successfully integrate research results into policies or practices. Only through cooperation can systems and policies be developed that are most beneficial to caregivers.

Implications

- The findings of this study can help in identifying factors related to the stress on parents of children having Autism Spectrum Disorder. In addition, it could serve as a channel for parent-organized self-help groups at many special educational institutions.
- The results of the present study may be applied to clinical practice to distinguish parents facing stress at distinct levels.
- From these results some recommendations can be made for the health department and social agencies working with families of children who have ASD. For this, we would have to provide services with personnel and other facilities at low prices that could improve their quality of life.

- Clinical support work should also be directed at solving parents 'psychological issues. Mental health professionals and clinicians should work out customized psychological treatment, consultation, and rehabilitation for caregivers to ease their burden.
- Considering all the misconceptions people have about ASD, this study should help to make them more aware of what it is like being a parent or caregiver with an autistic child. This would help elucidate the challenges and stresses of primary ASD caregivers.
- It can also guide quality-of-life interventions, and services like caregiver counseling, and support group programs.
- The study also may help identify predisposing factors for psychological problems of primary caregivers, such as the weight of going through special children education; social solitude and loneliness in parents; or economic distress.
- These findings might also be helpful to influence other studies of the relationship between ASD and caregiver mental health, helping future research.

References

Abd-Alnabi, A. L., & Sachet, K. R. (2022). Assessment of Quality of Life among Parents with Autistic Child. *Pakistan Journal of Medical & Health Sciences*, *16*(03), 964-964.

Abdul-Nabi, A. L., & Sachit, K. R. (2022). Relationship between psychological adjustment and quality of life among parents with autistic child. *International Journal of Health Sciences*, 3660–3666. https://doi.org/10.53730/ijhs.v6ns5.8838

Alhazmi, A., Petersen, R., & Donald, K. A. (2018). Quality of life among parents of South African children with autism spectrum disorder. *Acta neuropsychiatrica*, *30*(4), 226-231.

Ali, A. M., & Green, J. (2019). Factor structure of the depression anxiety stress Scale-21 (DASS-21): Unidimensionality of the Arabic version among Egyptian drug users. *Substance abuse treatment, prevention, and policy*, *14*, 1-8.

Althiabi, Y. (2021). Attitude, anxiety, and perceived mental health care needs among parents of children with Autism Spectrum Disorder (ASD) in Saudi Arabia during COVID-19 pandemic. *Research in Developmental Disabilities*, *111*, 103873. https://doi.org/10.1016/j.ridd.2021.103873

Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, *47*(2), 551–561. https://doi.org/10.1037/a0021268

Batool, S. S., & Khurshid, S. (2015). Factors associated with stress among parents of children with autism. *Journal of the College of Physicians and Surgeons Pakistan*, *25*(10), 752-756.

Bhandari, R., Paliwal, J. K., & Kuhad, A. (2020). Neuropsychopathology of autism spectrum disorder: complex interplay of genetic, epigenetic, and environmental factors. *Personalized Food Intervention and Therapy for Autism Spectrum Disorder Management*, 97-141.

Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in mental health nursing*, *37*(3), 153-163.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status, and satisfaction with services. *Autism*, 8, 409-423.

Brown, I., Neikrug, S., & Brown, R. I. (2000). Family quality of life survey. *International Family Quality of Life Project: Australia, Canada, Israel*.

Cassidy, A., McConkey, R., Truesdale-Kennedy, M., & Slevin, E. (2008). Preschoolers with autism spectrum disorders: The impact on families and the supports available to them. *Early Child Development and Care*, *178*(2), 115-128.

Chan, K. K. S., & Leung, D. C. K. (2020). The impact of child autistic symptoms on parental marital relationship: Parenting and co-parenting processes as mediating mechanisms. *Autism Research*, *13*(9), 1516-1526.

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

Clark, L. A., & Watson, D. (1991). Tripartite model of anxiety and depression: Psychometric evidence and taxonomic implications. *Journal of Abnormal Psychology*, 100(3), 316–336.

Constantino, J. N., Abbacchi, A. M., Saulnier, C., Klaiman, C., Mandell, D. S., Zhang, Y., ... & Geschwind, D. H. (2020). Timing of the diagnosis of autism in African American children. *Pediatrics*, *146*(3).

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.

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community mental health journal*, *37*, 39-52.

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of autism and developmental disorders, 40*, 1274-1284.

Estes, A., Olson, E., Sullivan, K., Greenson, J., Winter, J., Dawson, G., & Munson, J. (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain and Development*, *35*(2), 133-138.

Hayes, S. A., & Watson, S. L. (2012). The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children With and Without Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 43*(3), 629–642. https://doi.org/10.1007/s10803-012-1604-y

Henry, J. D., & Crawford, J. R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British journal of clinical psychology*, *44*(2), 227-239.

Hohlfeld, A. S., Harty, M., & Engel, M. E. (2018). Parents of children with disabilities: A systematic review of parenting interventions and self-efficacy. *African journal of disability*, *7*(1), 1-12.

Holly, L. E., Fenley, A. R., Kritikos, T. K., Merson, R. A., Abidin, R. R., & Langer, D. A. (2019). Evidence-base update for parenting stress measures in clinical samples. *Journal of Clinical Child & Adolescent Psychology*, *48*(5), 685-705.

Hsiao, Y. J., Higgins, K., Pierce, T., Whitby, P. J. S., & Tandy, R. D. (2017). Parental stress, family quality of life, and family-teacher partnerships: Families of children with autism spectrum disorder. *Research in developmental disabilities*, *70,* 152-162.

Huang, C. Y., Yen, H. C., Tseng, M. H., Tung, L. C., Chen, Y. D., & Chen, K. L. (2014). Impacts of autistic behaviors, emotional and behavioral problems on parenting stress in caregivers of children with autism. *Journal of Autism and Developmental Disorders*, *44*, 1383-1390.

Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: parenting stress, family functioning and health-related quality of life. *Families, systems, & health*, *29*(3), 232.

Kalaivnai, P., & Kalimo, K. M. (2018). A study on psychological problems faced by the parents of autism children. *Arts and Social Sciences Journal*, 9(4), 1–5.

Kalb, L. G., Badillo-Goicoechea, E., Holingue, C., Riehm, K. E., Thrul, J., Stuart, E. A., Smail, E. J., Law, K., White-Lehman, C., & Fallin, D. (2021). Psychological distress among caregivers raising a child with autism spectrum disorder during the COVID -19 pandemic. *Autism Research*, *14*(10). https://doi.org/10.1002/aur.2589

Karaivazoglou, K., Papadaki, E., Iconomou, G., Touliatos, G., Kotsopoulos, S., & Assimakopoulos, K. (2019). Psychological distress and health-related quality of life in parents of children referred to an outpatient service for children with developmental disorders. *Australasian Psychiatry*, *27*(2), 152-156.

Kaslow, N. J., Broth, M. R., Smith, C. O., & Collins, M. H. (2012). Family-based interventions for child and adolescent disorders. *Journal of marital and Family therapy*, *38*(1), 82-100.

Kausar, N., Akram, B., Dawood, S., & Ahmad, F. (2019) Socio-demographic Variables and Parental Stress of Children with Autism Spectrum Disorder. *Pakistan Journal of Social Issues.*

Khan, M. A., Zahid, R., & Ahmad, M. (2022). Locus of Control, Perceived Social Support and Quality of Life between Mothers of Autism Spectrum Disorder and Mainstream Children. *Pakistan Journal of Social and Clinical Psychology*, *20*(2), 41-47.

Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2010). Assessment of Health-Related Quality of Life Among Primary Caregivers of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *41*(9), 1214–1227. https://doi.org/10.1007/s10803-010-1140-6

Kissel, S. D., & Nelson III, W. M. (2016). Parents' perceptions of the severity of their child's autistic behaviors and differences in parental stress, family functioning, and social support. *Focus on Autism and Other Developmental Disabilities*, *31*(2), 152-160.

Lai, W. W., Goh, T. J., Oei, T. P. S., & Sung, M. (2015). Coping and Well-Being in Parents of Children with Autism Spectrum Disorders (ASD). *Journal of Autism and Developmental Disorders*, *45*(8), 2582–2593. https://doi.org/10.1007/s10803-015-2430-9

Machado, S. B. J., Celestino, M. I. O., & Serra, J. P. C., Caron, J., & Pondé, MP (2016). Risk and protective factors for symptoms of anxiety and depression in parents of children with autism spectrum disorder. *Developmental Neurorehabilition*, *19*(3), 146-153.

McClintock K., Hall S., Oliver C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: A meta-analytic study. *Journal of Intellectual Disability Research*, 47, 405–416.

Miodrag, N., & Hodapp, R. M. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current opinion in psychiatry*, *23*(5), 407-411.

Mohamad Aun, N. S., Zakaria, S. M., Ahmad Badayai, A. R., Idris, I. B., Daud, M., T. I., & Mohd Fazree, S. D. (2022). Quality of life among mothers of high Functioning Autism Spectrum Disorder (HFASD) adolescents. International Journal of Environmental Research and Public Health, 19(11), 6663

Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, *119*(5), e1040-e1046.

Mumtaz, N., Fatima, T., & Saqulain, G. (2022). Perception of Burden and Stress Among Mothers of Autistic Children in Pakistani Cultural Background. *Iranian Rehabilitation Journal*, *20*(1), 43-52.

Naheed, A., Islam, M. S., Hossain, S. W., Ahmed, H. U., Uddin, M. J., Tofail, F., ... & Munir, K. (2020). Burden of major depressive disorder and quality of life among mothers of children with autism spectrum disorder in urban bangladesh. *Autism Research*, *13*(2), 284-297.

Nikmat, A. W., Ahmad, M., Oon, N. L., & Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. *ASEAN Journal of Psychiatry*, *9*(2), 65-72.

Papadopoulos, A., Siafaka, V., Tsapara, A., Tafiadis, D., Kotsis, K., Skapinakis, P., & Tzoufi, M. (2023). Measuring parental stress, illness perceptions, coping and quality of life in families of children newly diagnosed with autism spectrum disorder. *BJPsych Open*, *9*(3), e84.

Park, S. H., Song, Y. J. C., Demetriou, E. A., Pepper, K. L., Norton, A., Thomas, E. E., ... & Guastella, A. J. (2019). Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress. Autism, 23(7), 1675-1686.

Park. D., Choi. J., (2022). Effect of Challenging Behaviors of Children with ASD on Their Parents' Quality of Life: The Moderating Effect of Stress Coping Style. *Journal of the Korean Association for Persons with Autism,* 22(2):93-114. doi: 10.33729/kapa.2022.2.4

Patel, A. D., Arya, A., Agarwal, V., Gupta, P. K., & Agarwal, M. (2022). Burden of care and quality of life in caregivers of children and adolescents with autism spectrum disorder. *Asian Journal of Psychiatry*, *70*, 103030.

Perumal, V., Veeraraghavan, V., & Lekhra, O. P. (2014). Quality of life in families of children with autism spectrum disorder in India. *Journal of Pharmacy Research*, *8*(6), 791-797.

Peters-Scheffer, N., Didden, R., & Korzilius, H. (2012). Maternal stress predicted by characteristics of children with autism spectrum disorder and intellectual disability. *Research in Autism Spectrum Disorders*, *6*(2), 696-706.

Picardi, A., Gigantesco, A., Tarolla, E., Stoppioni, V., Cerbo, R., Cremonte, M., Alessandri, G., Lega, I., & Nardocci, F. (2018). Parental Burden and its Correlates in Families of Children with Autism Spectrum Disorder: A Multicentre Study with Two Comparison

Groups. *Clinical Practice & Epidemiology in Mental Health*, *14*(1), 143–176. https://doi.org/10.2174/1745017901814010143

Predescu, E. and Şipoş, R. (2013) Cognitive coping strategies, emotional distress and quality of life in mothers of children with ASD and ADHD—A comparative study in a Romanian population sample. *Open Journal of Psychiatry*, 3, 11-17.

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., ... & Wood, E. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC pediatrics*, *4*, 1-13.

Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior modification*, *33*(4), 437-451.

Romero, M., Marín, E., Guzmán-Parra, J., Navas, P., Aguilar, J. M., Lara, J. P., & Barbancho, M. Á. (2021). Relationship between parental stress and psychological distress and emotional and behavioural problems in pre-school children with autistic spectrum disorder. *Anales de Pediatría (English Edition)*, *94*(2), 99–106. https://doi.org/10.1016/j.anpede.2020.03.014

Schieve, L. A., Boulet, S. L., Kogan, M. D., Yeargin-Allsopp, M., Boyle, C. A., Visser, S. N., ... & Rice, C. (2011). Parenting aggravation and autism spectrum disorders: 2007 National Survey of Children’s Health. *Disability and health journal*, *4*(3), 143-152.

Schnabel, A., Youssef, G. J., Hallford, D. J., Hartley, E. J., McGillivray, J. A., Stewart, M., Forbes, D., & Austin, D. W. (2019). Psychopathology in parents of children with autism spectrum disorder: A systematic review and meta-analysis of prevalence. *Autism*, *24*(1), 26–40. https://doi.org/10.1177/1362361319844636

Ten Hoopen, L. W., de Nijs, P. F. A., Duvekot, J., Greaves-Lord, K., Hillegers, M. H. J., Brouwer, W. B. F., & Hakkaart-van Roijen, L. (2019). Children with an Autism Spectrum Disorder and Their Caregivers: Capturing Health-Related and Care-Related Quality of Life. *Journal of Autism and Developmental Disorders*, *50*(1), 263–277. https://doi.org/10.1007/s10803-019-04249-w

Tomeny, T. S., Baker, L. K., Barry, T. D., Eldred, S. W., & Rankin, J. A. (2016). Emotional and behavioral functioning of typically-developing sisters of children with autism spectrum disorder: The roles of ASD severity, parental stress, and marital status. *Research in Autism Spectrum Disorders*, *32*, 130-142.

Van Steijn, D. J., Oerlemans, A. M., van Aken, M. A. G., Buitelaar, J. K., & Rommelse, N. N. J. (2013). The Reciprocal Relationship of ASD, ADHD, Depressive Symptoms and Stress in Parents of Children with ASD and/or ADHD. *Journal of Autism and Developmental Disorders*, *44*(5), 1064–1076. https://doi.org/10.1007/s10803-013-1958-9

Waheed, A., Khan, M. J., & Khurshid, M. (2020). EFFECT OF BEHAVIORAL PROBLEMS OF CHILDREN WITH AUTISM ON THEIR MOTHER'S QUALITY OF LIFE. *Pakistan Armed Forces Medical Journal*, *70*(6), 1666-70.

Whoqol Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological medicine*, *28*(3), 551-558.

Wolstencroft, J., Srinivasan, R., Hall, J., van den Bree, M. B. M., Owen, M. J., Raymond, F. L., & Skuse, D. (2023). Mental health impact of autism on families of children with intellectual and developmental disabilities of genetic origin. *JCPP Advances*, *3*(1). https://doi.org/10.1002/jcv2.12128

Yu, Y. W., Chung, K. H., Lee, Y. K., Lam, W. C., & Yiu, M. G. C. (2016). Prevalence of maternal affective disorders in Chinese mothers of preschool children with autism spectrum disorders. *East Asian Archives of Psychiatry*, *26*(4), 121-128.

Appendix A Informed Consent

Informed Consent

Dear Participant,

I am a BS Psychology student from COMSATS University Islamabad, Lahore Campus, conducting a research study to investigate the “Psychological problems and quality of life in primary caregivers of children with Autism Spectrum Disorder”. Your participation in this study is greatly appreciated. The questionnaire consists of four sections and should take approximately 10-15 minutes to complete. Your participation is voluntary, and you have the right to withdraw at any time without penalty or consequence. All information provided will be kept confidential and only used for research purposes. Please be assured that your anonymity and privacy will be maintained throughout the study. Please note that there are no known risks associated with participating in this study, and it is completely anonymous. However, if you experience any discomfort or distress while filling out the questionnaire, you may choose to skip any questions or stop the survey altogether. If you have any questions or concerns about the study or the questionnaire, please feel free to contact me. Thank you for your cooperation and valuable contribution to this study.

Signature of Participant: ___________ **Signature of Researcher:** _____________

Appendix B Demographic Sheet

Demographic Sheet

Personal Information

Age of Parent (In Years): _______ **Gender:** Male Female
Age of Child (In Years)
Family System: Nuclear Joint
Number of Siblings of child (Including the Child): ________
Birth Order of Child: _________
Area of Residence: Rural Urban **Family Income (Rs): ___________**
Parents Employment Status:

Academic Information of Parent

Educational Background
Educated Uneducated
Completed Levels of Education (If educated)
Matric Intermediate Graduate Post-Graduate

Appendix C Depression, Anxiety, Stress Scale (DASS-21)

DASS-21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The *rating scale* is as follows:

0: **Did not apply to me at all**

1: **Applied to me to some degree, or some of the time**

2: **Applied to me to a considerable degree, or a good part of time**

3: **Applied to me very much, or most of the time**

Statements	**Did not apply to me at all**	**Applied to me to some of the time**	**Applied to me to a good part of time**	**Applied to me most of the time**
1. I found it hard to wind down.	0	1	2	3
2. I was aware of dryness of my mouth.	0	1	2	3
3. I couldn't seem to experience any positive feeling at all.	0	1	2	3

4. I experienced breathing difficulty (e.g, excessively rapid breathing, breathlessness in the absence of physical exertion).	0	1	2	3
5. I found it difficult to work up the initiative to do things.	0	1	2	3
6. I tended to over-react to situations.	0	1	2	3
7. I experienced trembling (e.g, in the hands).	0	1	2	3
8. I felt that I was using a lot of nervous energy.	0	1	2	3
9. I was worried about situations in which I might panic and make a fool of myself.	0	1	2	3
10. I felt that I had nothing to look forward to.	0	1	2	3
11. I found myself getting agitated.	0	1	2	3
12. I found it difficult to relax.	0	1	2	3
13. I felt down-hearted and blue.	0	1	2	3

14. I was intolerant of anything that kept me from getting on with what I was doing.	0	1	2	3
15. I felt I was close to panic.	0	1	2	3
16. I was unable to become enthusiastic about anything.	0	1	2	3
17. I felt I wasn't worth much as a person.	0	1	2	3
18. I felt that I was rather touchy.	0	1	2	3
19. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat).	0	1	2	3
20. I felt scared without any good reason.	0	1	2	3
21. I felt that life was meaningless.	0	1	2	3

Appendix D World Health Organization- Quality of Life Scale (WHO-QOL-BREF)

WHO-QOL-BREF Scale

This assessment asks how you feel about your quality of life, health, and other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

Please read the question, assess your feelings, for the last two weeks, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
● How would you rate your quality of life?	1	2	3	4	5
	Very dissatisfied	**Fairly Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
● How satisfied are you with your health?	1	2	3	4	5
The following questions ask about how much you have experienced certain things in **<u>last two weeks</u>**.					

	Not at all	**A Small amount**	**A Moderate amount**	**A great deal**	**An Extreme amount**
● To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
● How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
● How much do you enjoy life?	1	2	3	4	5
● To what extent do you feel your life to be meaningful?	1	2	3	4	5

	Not at all	**Slightly**	**Moderately**	**Very**	**Extremely**
● How well are you able to concentrate?	1	2	3	4	5
● How safe do you feel in your daily life?	1	2	3	4	5
● healthy is your physical environment?	1	2	3	4	5

	Not at all	**Slightly**	**Somewhat**	**To a great extent**	**Completely**
● Do you have enough energy for everyday life?	1	2	3	4	5
● Are you able to accept your bodily appearance?	1	2	3	4	5
● Have you enough money to meet your needs?	1	2	3	4	5
● How available to you is the information you need in your daily life?	1	2	3	4	5
● To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	Not at all	**Slightly**	**Moderately**	**Very**	**Extremely**
● How well are you able to get around physically?	1	2	3	4	5
The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the over the **last two weeks**.					
	Very Dissatisfied	**Fairly Dissatisfied**	**Neither Satisfied nor Dissatisfied**	**Satisfied**	**Very satisfied**
● How satisfied are you with your sleep?	1	2	3	4	5

● How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
● How satisfied are you with your capacity for work	1	2	3	4	5
● How satisfied are you with yourself?	1	2	3	4	5
● How satisfied are you with your personal relationships?	1	2	3	4	5
● How satisfied are you with your sex life?	1	2	3	4	5

● How satisfied are you with the support you get from your friends?	1	2	3	4	5
● How satisfied are you with the conditions of your living place?	1	2	3	4	5
● How satisfied are you with your access to health services?	1	2	3	4	5
● How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

	Never	**In-frequently**	**Sometimes**	**Frequently**	**Always**
● How often do you have negative feelings such as blue mood, despair, anxiety or depression?	1	2	3	4	5

Appendix E Author's Permission Letters

Appendix F Data Collection Permission Letters

Appendix G Plagiarism Report

Appendix H Checklist