

Challenges Faced by Parents Raising Children with Autism Spectrum Disorder: A Qualitative Study in Pakistan

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ABSTRACT

The aim of this qualitative study was to explore multifaceted issues in parents raising a child with autism spectrum Disorder ASD. An interpretative phenomenological analysis IPA method was used to measure the lived experiences of the parents. Permission was taken from the group admin in the platform entitled Autism Resource Group Pakistan on WhatsApp, in this group parents across the country are added for the facilitation to better provide the care for their children. Online in-depth interviews were conducted with the participants. Purposive sampling technique was used for the data collection and the sample size for the current was 12 (n=12) individuals with equal number of representations from the male (father) =6 and female (mother) =6. All of them were the parents having at least a child with autism spectrum disorder. The interviews were recorded and transcribed later. After the transcription and analysis phase, different themes were identified as, psychological issues, social issues, health related issues, and Occupational or work-related issues. Lastly those who are practicing, making policies and regulatory bodies should consider urgently issues explored in this study and mentioned as themes so that they could provide proper healthcare essential services for parents and children with autism.

Keywords: Multifaceted issues, ASD, IPA Analysis

INTRODUCTION

Autism Spectrum Disorder (ASD), which is a multifaceted neurodevelopmental disorder, is seen as having difficulties in social communication and interaction, as well as restricted repetitive behaviors, interests or activities (Schneider, 2013). The disorder has a wide range of severity and presentation which often referred to as a spectrum that includes individuals with high functioning autism (previously known as Asperger syndrome) to those with profound intellectual disability and significant impairment in daily functioning (Lai et al., 2014). The prevalence of ASD has been increasing worldwide. Recent estimates indicate that one out of every 36 children in the United States is diagnosed with ASD. While Pakistan-specific comparable prevalence rates are poorly documented; studies from neighboring countries like India show similar prevalence patterns (Hyman et al., 2020).

Families may also encounter negative attitudes found among their communities which hinder them from accessing support networks and inclusive social environments for their kids (Kasperzack et al., 2019).

This lack of awareness and acceptance towards neurodiversity caused shame and guilt among parents leading to mental health issues for example depression (Lai et al., 2014b). Psychologically compared to parents whose children develop typically those who raise autistic ones experience increased levels of psychological distress (Alibekova et al., 2022a). Caregiving-related constant duties plus uncertainty of what happens to the child in future lead to anxiety, depression and chronic stress (Papadopoulos, 2021). In a country like Pakistan where mental health resources are limited and access to psychological support services is challenging, these problems have a great impact on parents' life (Nadeem et al., 2024a).

According to research in this area indicates that parents of children with autism were more likely than those without autistic children to report higher levels of stress and psychological distress. Some causes include ambiguity surrounding autism diagnoses, the long-term prognosis, the stressful nature of symptoms associated with behavior problems, and a lack of public understanding or tolerance (Makino et al., 2021). This results in what Befi et al. (2023) call a loss of sense around self-image, identity, and livelihood, leading to altered hopes, dreams, and expectations in parenting.

Bonis & Sawin (2016) asserts that the challenges faced by parents of autistic children disrupt their family life and potentially impact their marital relationships. Quatrosi et al. (2023) report that this disorder also negatively affects their siblings, according to Papadopoulos (2021), factors such as maternal stress, physical tiredness, lack of time, and coping with children's behaviors may have a negative impact on intimacy between couples because they can interfere with an individual's ability to balance life regarding therapies and manage other children. Still, some researchers (Depape & Lindsay, 2014; Lee & Chiang, 2018) hold the view that marital relations among such parents face certain difficulties. Autism disrupts sleeping arrangements, work, meals, or time spent away from the child, resulting in more quarrels and impatience. According to Greenlee et al. (2022) conducted research that showed one-third of parents report difficulty in marriage due to persistent fights in the house, denial of autism diagnosis, and demands of caring for them. Moreover, compared to typically developing children, divorce rates are higher among parents of autistic kids (He et al., 2022). Nevertheless, there are also studies showing that family structures remain strong even despite this pressure (Parton et al., 2024). The diagnosis of autism affects not only kids but also their siblings, who become jealous because it seems like all attention is directed towards a child suffering from autism, thus ignoring them (Parton et al., 2024).

Caring for a special needs child costs more than raising a typical child. This means that families living with autistic children experience high costs in terms of medical care provisions as well as education, while at the same time limiting employment prospects (Piro-Gambetti et al., 2023). Research reveals those mothers' careers suffer, leading many to restrict their career options or quit their jobs entirely (Jenkins et al., 2005). People with mental disorders, including autism, face a social stigma that affects their overall social environment (Lynch et al., 2023). Stigma is a global phenomenon that refers to the discrediting traits that destroy our sense of self and identity (Alareeki et al., 2022). For instance, Kütük et al. (2021), argues about disruptive behaviors and a lack of understanding among some members of the public, leaving most parents feeling socially stigmatized. Professionals in service delivery in Mexico discriminate against mothers, as do strangers (Nadeem et al., 2024b).

METHODOLOGY

Research Design

For this study, qualitative research was being followed, further the Interpretative phenomenological analysis IPA method has been adopted.

Sample and Sampling

Purposive sampling (Hardesty et al., 2022) was used and the sample size for this study was 12 participants parents, with equal representation of male (6) and Female (6). Morse (2015) recommended the use of six sample sizes for interpretative phenomenological analysis IPA. Smith et al. (2021) also recommended a minimum number of participants for interpretative phenomenological analysis IPA research.

Participants

For the current study the participants were the parents having ASD Child/Children.

Inclusion & Exclusion Criteria

Parents who have at least one/more child/children diagnosed with autism spectrum disorder (ASD), are educated, are either job holders or own a business, and are not diagnosed with any chronic psychological, or health-related issues, and do not have any disabilities. The age range was 18 years to 50 years. Parents who were divorced, stepparents or foster parents, those diagnosed with chronic mental or health-related issues, and who are below 18 years or above 50 years of age.

Measures

Semi-Structure in depth interview was conducted with parents. According to Crouch & McKenzie (2006) In-depth interviews expose real-life questions and provide rich knowledge.

Procedure

The data was collected through from a sample using a WhatsApp group named “Autism Resource Group Pakistan” a social media platform both available on Facebook and WhatsApp which is made for the parents (Pakistani parents from Pakistan and outside Pakistan are added) as resource group where parents and experts (Psychologists, Speech & Language therapists, Special educationists etc.) are added for facilitations or sharing the information. Prior to the approval of the platform officials, the consent was obtained from the willing parents to participate in this study. Online Interviews were conducted with the parents.

Data Transcription & Analysis

The interviews were recorded and later transcribed manually. Once the data was recorded and transcribed the Interpretative phenomenological analysis was done with the data. Interpretative phenomenological analysis is a method that is used to collect detailed or in-depth analysis of the lived experiences. This method ensures that the participants shared detailed personal experiences or lived experience that can be complex in nature and may have the emotional implications (Smith & Osborn, 2015). The data analysis process followed a seven-step procedure: (Smith et al., 2021) given seven steps for the IPA analysis, for the current study seven steps were followed as below.

1. The data was read and reread several times to make self-familiar with the information.
2. The separate page was used to note down the significant notes.
3. Various themes were identified, the transcript was highlighted, the numbers were assign to themes to quote it easily.
4. By grouping the similar themes in clusters, the superordinate themes were created.
5. The same method was followed moving to the next cases in each one.
6. Checking for similarities that is of higher order qualities in the cases were again integrated.
7. Analysis being final step; important themes were described with verbatim.

Ethical Considerations

The confidentiality of the identifying data or information that can identify the client to the public was considered and secured that no one can recognize the clients. Numbers are used instead of the original name. Participants were treated with respect and equality. This study did not include any minor or major harm to the participants.

RESULT

Table 1: Demographic Information

S.No	Name	Gender	Age	Occupation	Child Age
1	P1(F)	Female	38	Dermatologist Dr.	4
2	P2(F)	Female	40	Housewife	5,9
3	P3(F)	Female	27	Statistics teacher Higher education	4,6
4	P4(F)	Female	31	Relationship Manager MCB Bank	7
5	P5(F)	Female	31	LHV	4,8
6	P6(F)	Female	27	Government School teacher	6
7	P1(M)	Male	35	Manager Private Firm	5
8	P2(M)	Male	34	Biology Teacher College	4.5
9	P3(M)	Male	40	Sports business	5
10	P4(M)	Male	45	filtered water business	3.5
11	P5(M)	Male	28	NGO Social Mobilizer	5
12	P6(M)	Male	43	Manager at Coca-Cola	5, 9

Table 2: Multifaceted Issues in Parenting

Theme	Operationalization	Code	Operationalization
Psychological Issues	Refers to the mental and emotional toll experienced by parents, including symptoms of stress, depression, anxiety, and difficulties in emotional regulation due to caregiving responsibilities.	Emotional and Mental Strain	Feelings of being overwhelmed, emotionally drained, or mentally exhausted from caregiving.
		Mood Disorders	Experiences of clinical or subclinical symptoms of depression, anxiety, or persistent low mood.
		Emotional Impact of Diagnosis	Initial and ongoing emotional reactions (e.g., denial, grief, shock) upon learning the child's ASD diagnosis.
		Emotional Instability	Rapid mood fluctuations, difficulty managing emotions, and increased emotional sensitivity or reactivity.
Social Issues	Covers disruptions in parents' social life and interactions, including social withdrawal, stigma, and changes in support networks.	Social Relationships	Changes in the quality or quantity of relationships with family, friends, or community due to caregiving.
		Social Isolation and	Experiences of feeling alone, unsupported, or excluded from

		Support	social circles or family systems.
		Social Stigma & Judgement	Perceived or actual criticism, labeling, or negative societal attitudes towards the parent or child.
		Avoidance of Social Situations	Intentional withdrawal or refusal to participate in public or family gatherings due to fear of judgment or stress.
Occupation/Work-Related Issues	Explores the impact of caregiving on work performance, job security, finances, and career aspirations	Work-Life Balance and Impact	Difficulties managing job responsibilities alongside caregiving, leading to imbalance or conflict.
		Financial Stress	Strain caused by increased expenses related to the child's care and/or reduced income.
		Workplace Challenges	Employer misunderstanding, lack of accommodations, or job inflexibility due to caregiving needs.
		Work Attendance and Performance Underlying Work Pressure	Absenteeism, tardiness, or decreased productivity at work as a result of caregiving demands. Hidden stress from trying to maintain professionalism while dealing with home responsibilities.
Health-Related Issues	Addresses the physical health effects of long-term stress, including fatigue, poor sleep, and stress-related illnesses.	Sleep and Energy Issues	Insomnia, poor sleep quality, or persistent fatigue experienced by the parent.
		Stress-Related Physical Symptoms	Physical issues such as headaches, high blood pressure, or muscle tension resulting from chronic stress.
		Immune and Digestive Health Physical Exhaustion and Weight	Frequent illness, weakened immunity, or digestive issues exacerbated by stress. Reports of feeling physically drained or experiencing changes in weight due to caregiving pressures.

Theme 1: Psychological issues

Code: Emotional and Mental Strain

The participants stated that their mental health has been impacted and emotional ups and downs have taken a toll on their mental health. They reported that they feel stressed, and they are also mentally

exhausted and feel overwhelmed due the ongoing tough care of the child/children with autism spectrum disorder. According to P1 (F), *"Having an autistic child has significantly impacted my overall mental health and well-being. It has been a journey filled with both rewarding moments and intense challenges. The constant need to be vigilant and the emotional ups and downs have taken a toll on my mental health. There are days when I feel overwhelmed and exhausted, but I also find moments of immense joy and pride in my son's progress."* P1 (F), P12 (M) also stated that; *"The stress of managing daily routines, dealing with meltdowns, and ensuring that both children are getting the support they need can be overwhelming."* P12 (M)

Code: Mood Disorders

Participant stated that they have the feelings of anxiety and feelings of depression, they reported that they often feel worried about their children, they think that what will be the future of third kids, they are also depressed due to the care that is very tough and demanding in nature. They stated that their moods are in sad often due to raising a child with autism spectrum disorder. According to P10 (M); *"Yes, the constant care and attention required have caused me to feel stressed and anxious. There are times when the demands feel overwhelming, and it's easy to slip into feelings of depression, especially when progress seems slow or when facing societal judgment."* P10 (M)

Code: Emotional Impact of Diagnosis

The parents indicated that their child's diagnosis had had a profound and multidimensional impact on them. According to the parents that they experience a sense of loss and sadness after they know that their child is diagnosed with autism spectrum disorder, which was interlaced with an initial emotional shock. By receiving the diagnosis, the parents overcome with disbelief and distress as they faced the reality of their child's circumstances. They also report that it was an emotional shock for them that their child is diagnosed, it signaled the beginning of a difficult time that is defined by strong emotional turmoil and a deeper sense of grief over the loss of their child's expected future. P2 (F) elaborated as below; *"Yes, when both of my children were diagnosed, I felt a deep sense of sadness and loss. I was in very grief as I hoped and imagined a different future and the realization of life for my children, but it couldn't be the same."* P2 (F), P12 (M) has also stated that; *"I was in a shock due to the initial diagnosis, it created a lot of uncertainty and the fear about the future of child or own self."* P12 (M)

Code: Emotional Instability

Parents reported that when caring for a child with autism spectrum disorder that is like a roller coaster ride that is consisted of ups and downs and uncertainty. They also said that the journey begun with emotional shock and that was linked with the diagnosis, and it continues through the tough and easy times and periods. They also reported that their lives are filled with number of difficulties and hardships and that is alternating between the hope and despair. An addition to that they said that there has also been a continual sensation of uncertainty, that is the worry and the tension about the condition of the child and its. They described their lives as filled with countless hardships and alternating between hope and despair. Furthermore, there had been a continual sensation of uncertainty, that is tension and worry about their child's condition and its impact. According to P10 (M); *"Ahm! I was in a shock and that was very huge shock due the initial diagnosis of my child. After that the journey has been of ups and downs since the initial diagnosis. While there are moments of joy and pride, there are also times of intense stress and worry about my child's future. Hm!! Balancing these emotions is challenging and can be exhausting."* P10 (M)

Theme 2: Social Issues

Code: Disintegration of Social Relationships

The parents reported that their social relationships changed, and their social circle also shrinks, and many other issues occurred. The diagnosis of their child resulted in substantial alterations in their social contacts and relationships. Many parents discovered that their social ties had changed because of misunderstandings and a lack of support from their larger social network. As a result, they experienced a shrinking of their social circle, withdrawing from social activities and contacts that no longer felt supportive or understanding of their specific issues. According to P3 (F); *“Raising children with autism has significantly impacted my social relationships. Initially, many of my friends and even some family members didn’t understand the challenges we face. Some distanced themselves because they didn’t know how to react or support us.”* P3 (F), P5 (F) also stated as; *“Initially, some family members and friends didn’t understand the challenges we were facing. They would sometimes make insensitive remarks or give unsolicited advice. Over time, I found that my social circle became smaller. Only those who truly wanted to understand and support us remained close. On the positive side, the relationships that did endure have become much stronger and more meaningful.”* P5 (F)

Code: Social Isolation and Support

Parents frequently experienced social isolation and a lack of support. Many reported a lack of social connections, which aggravated their sense of loneliness. This lack of social support left parents feeling isolated in their troubles, as they had few people to turn to who fully understood their experiences and challenges. As a result, the lack of a solid support structure had a severe influence on their emotional and mental health. According to P7 (M), *“It’s challenging to maintain social ties when we must prioritize my son’s needs, which means missing out on social gatherings or family events. The lack of understanding from some people about autism has created a gap in some of our relationships.”* P7 (M), According to P8 (M), *“We’ve had to limit our social interactions because it’s challenging to explain our son’s behavior to those who are not familiar with autism. This has, unfortunately, led to a sense of isolation at times.”* P8 (M), According to P3 (F), *“Many of my friends and even some family members didn’t understand the challenges we face. Some distanced themselves because they didn’t know how to react or support us”* P3 (F)

Code: Social Stigma & Judgement

Parents often faced judgment and disgrace from society. They experienced social stigma and criticism from others, which frequently took the form of teasing and unfavorable social reactions. A general lack of knowledge regarding autism spectrum disorder contributed to this stigma by causing misunderstandings and unfair treatment. Parents said that social mocking and unfavorable social reactions increased their emotional load and made it harder for them to go about their everyday lives and find acceptance and support in their communities. According to P1 (F), *“Unfortunately, yes. There have been instances where I’ve faced social stigma and judgment because of my child’s autism. People sometimes make assumptions about his behavior, and there have been hurtful comments and stares. It’s disheartening when others are quick to judge without understanding the context of his actions.”* P1 (F)

Code: Avoidance of Social Situations

Parents would frequently turn to social situation avoidance. This involved often turning down social invites and removing either themselves or their child from public places. The motivation behind these acts was to protect their child from potentially upsetting or judgmental surroundings as well as the discomfort and misunderstandings that frequently resulted from a lack of understanding and support from others. According to P6 (F); *“Most people are more understanding once they know the reason behind the behavior. However, there are times when it’s best to remove ourselves from the situation to prevent further*

stress for our child and ourselves.” P6 (F), P12 (M) also stated that; “Many of our friends and extended family members didn't understand what autism is and how it affects our children. This led to a sense of isolation, as we often had to decline social invitations or leave gatherings early because our children were overwhelmed.” P12 (M)

Theme 3: Occupational/Work Related Issues

Code: Work-Life Balance and Impact

Parents had to deal with a lot of professional and occupational problems with work-life balance and how it affected their professional lives. It became more difficult for them to maintain a healthy work-life balance as they balanced their child's critical care needs with the responsibilities of their employment. Due to this imbalance, schedules were frequently disrupted, which made it challenging to commit to long-term projects or regular working hours. Their work life was negatively impacted by frequent setbacks, decreased output, and a persistent battle to successfully balance work and personal commitments. According to P1 (F), *“Yes, balancing job and caregiving responsibilities is a constant struggle. There are days when my son requires more attention, and it becomes difficult to focus on work. The unpredictability of his needs means that I often must reschedule or cancel professional commitments at the last minute. This balancing act can be exhausting and sometimes feels like an impossible task, but it's something I continuously work on by prioritizing and managing time as effectively as possible.”* P1 (F), P4 (F) Also stated that; *“Parenting a child with autism has significantly impacted my work life. As a relationship manager at MCB Bank, my job requires a lot of focus and time, but there are days when my child's needs must take priority. This often means taking time off for appointments, therapies, or when my child needs extra support, which can affect my professional responsibilities and commitments.”* P4 (F), P11 (M) further added *“I often have to adjust the schedule, even at the last minutes of my work due to the unpredictability of the needs of my child. This is sometimes exhausting to balance, and it sometimes leads me to feel guilty for not being able to give 100 Percent to the job or to the needs of my child.”* P11 (M)

Code: Financial Stress

According to the parents they experience financial hardship and that can be tremendous. Parents experienced tremendous financial hardships. The hardship of the finance impact includes a decrease that can be in earning and that is because of the cutting the working hours of the both parents or even of a single parent, or even it includes the offs or leaving the jobs and caring for the child or children. It has increased the financial problems and the stress that increased expense of the needs of the child and include special therapies, treatments, and special educational facilitation.

The parents also stated that there is a lack of financial support from the social services or other sectors, which in return exacerbated the issues, that include forcing the parents to budgeting carefully and significantly making financial sacrifices. The sacrifices include the reduction of the personal items and forsaking long term financial goals that is for to provide their child with the required support and care they need. According to P2 (F), *“It is very big challenge for me to manage the financial stress and its related phenomenon. The expenses of the treatment facilities that include the therapies, special education, and some other support services can be difficult to manage and it stress me often. We are very cautious with our budget; we focus on the priorities which essential for our children development. The primary income source is only the earnings of my husband, we must make sacrifices on the children needs. We cut back on non-essential expenditure. We often try to get any financial assistance help available. But it is not much available or very limited.”* P2 (F)

Code: Workplace Challenges

Parents reported that they face numbers of employments issues and obstacles, which put a huge impact of their professional careers. The parents reported that many employers do not provide accommodation for the parents who are dealing with the special needs and demands of raising a child with autism spectrum disorder. They said the lack of this flexibility make it very difficult to manage both the employment and caregiving responsibilities. Or even balancing them appropriately.

They said if the employer is not supportive it exacerbates the difficulties, some companies can be unsympathetic or unresponsive to their requests regarding the flexibility or understanding their unique experiences in one way or another. They also reported that it is very difficult to communicate openly with employer regarding the issues they face, they said if we discuss with the employer and they do not agree, because of this they avoid discussing it. According to P9 (M), *"I do not have any issues as I run my own business, and have more flexibility as compared to any individual who is working for an employer. However, there are still issues and challenges my parents and clients do not understand that why I need to reschedule meetings or go away unexpectedly. I have not faced any direct discrimination; the lack of understanding is difficult to be navigate."* P9 (M)

Code: Work Attendance and Performance

Parents reported that they have the issues of work performance and the attendance. Some of the parents stated that they found themselves having to leave the work early or making frequent absences because of their child's unique and unpredictable needs and treatment related appointments and meetings. They said they are sometimes unable to balance the work and the caring commitments or responsibilities that often or frequently result in lower or poor productivity in workplace, it also leads to problems in satisfying the employer expectations. They said they are compelled to make frequent absences from the work, these were prompted by the need to provide the care to the child and treatments that include, visits to medical settings, therapies and educational sessions. The parents said the absence which are intentional or unplanned put an additional burden on the workload and they are frequently forced to manage their task efficiently to catch up the stream. They also reported that the unexpected nature of their children needs and conditions often led to sudden reduction or rescheduling of meeting and delay in completion of professional responsibilities etc. According to P5 (F); *"I have been facing the challenges in getting the accommodation unpredictably. For instance, in many cases I must leave the work early or taking offs on short notices, that is not always easy to arrange."* P5 (F), P2 (F) also stated that; *"Teaching requires a lot of preparation and focus, and there are times when my children's needs must come first, which can interfere with my work. Finding a balance between being there for my students and being the caregiver, my children need is one of the toughest aspects of my daily life."* P2 (F), According to P8 (M); *"There are days when I must leave work early or arrive late because of my son's needs. This often leads to increased workload and stress, as I try to keep up with my professional duties while ensuring that my son receives the care and attention he requires."* P8 (M); According to P10 (M); *"Parenting a child with autism has had a significant impact on my professional life. Running a business requires a lot of time and dedication, but my child's needs often require my immediate attention, which can disrupt my work schedule. There have been instances when I've had to leave work suddenly or decline important meetings to attend to my child's needs."* P10 (M).

Code: Underlying Work Pressure

According to parents they frequently face the underlying work-related pressure from one way or another. This pressure originates from expectation of the completion of the professional responsibility or tasks and obligations while dealing with the chronic personal issues that are related to caring for a child with autism spectrum disorder. Despite Having a lot of issues, they face it home related to caring that include organizing therapy schedules, medical appointments, and their child's daily needs which are unique and

difficult to manage easily, parents want to excel at their jobs. This pressure often results in stress, fatigue and perpetual running that act between satisfying professional obligations and meeting the family requirements. According to P12 (M); *"Ho! I feel a lot of pressure and that is related to perform well and meet the expectations and manage the needs of the child."* P12 (M)

Theme 4: Health related Issues

Code: Sleep and Energy Issues

According to the parents they have various kinds of health-related issues, they often reported issues related to sleep wake phenomenon. They said the insomnia is one of the widespread issues to them. They said we try to sleep but we due to the care and sometimes they worry, and stress related to childcare and responsibilities therefore they do not sleep well. They said due to the lack of proper sleep, it contributed to feeling of exhaustion, parents said they feel physically and psychologically exhausted on daily bases. They also reported a low level of energy, it is reported that the burden of caring put them on low level of energy, they said that this low energy often makes them limit to complete their responsibilities. The sleep and energy issues not only impacted their physical health, but it also impacted them emotionally and psychologically and it is a strain that put them on these issues that is related to the care for an ASD child. According to P8 (M); *"I face number physically and health related issues but one of them is insomnia, it is due to demands of caring for a child that often disrupt my sleep schedule, it also leads to the fatigue and other issues."* P8 (M)

Code: Stress-Related Physical Symptoms

According to parents they often face stress related issues and symptoms. They said that they face issues like, high blood pressure and that is major worry for them. They said they suffer blood pressure issues due to the stress and anxiety associated with the caring for children or child with autism spectrum disorder. Some of the parents also stated that they have frequent headaches which were also caused by the stress and anxiety of the parenting of an ASD child. They also reported that they have muscle related issues such as muscle tension, tightness or stiffness in muscles specifically in shoulders and neck, because of extended stress and physical fatigue due to the child they hold often when need or other parenting responsibilities. The number of cares giving responsibilities have various influence on the parents' physical health. According to P1 (F); *"Oho! It is very often; I face a lot of stress and physical fatigue and that is very prolonged. It caused me having blood pressure or I often have headaches, because of the parenting strain."* P1 (F), P11 (M) also elaborated; *"Hmm! I experience a lot of health-related concerns, one of them is muscle tension and fatigue on regular basis. And I believe these are because of the stress and parenting for my child."* P11 (M)

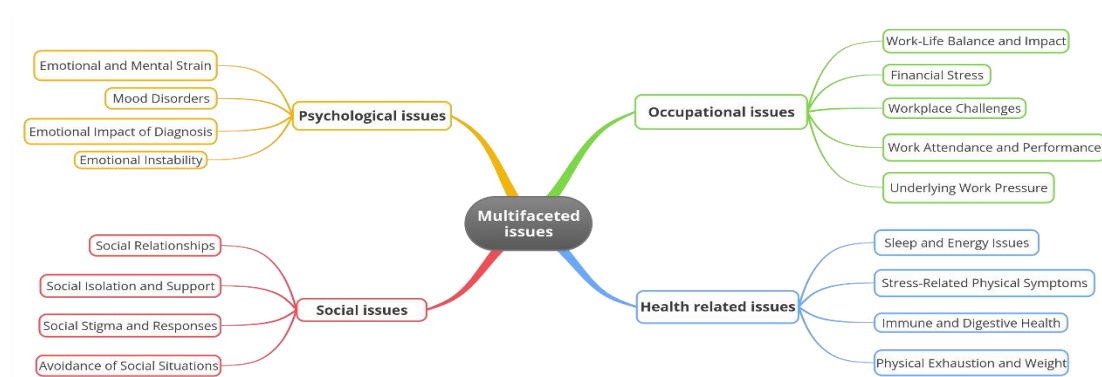
Code: Immune and Digestive Health

Parents reported that they have issues like intestinal or immunological. They said our immune system is become weak due the daily stress and parenting fatigue on them. They said due to the weak immune system the often fill ill or suffer many illnesses or infections. The mental strain and stress of parenting a child with autism spectrum disorder weakened their immune system over a period. They also reported digestive problems like pain in belly et. The parents reported that these issues were related to the stress they face, dietary changes, and irregular pattern of eating caused by the parenting or caregiving responsibilities for an ASD child. According to P12 (M); *"I am very stressful, and it impacted my physical health that leads often to frequent headaches, weakened immune system. I have notice that I fall ill more often, and recovery take longer time as compared to the past. I believe this is because of the stress and physical strain due to the parenting an ASD child."* P12 (M), P3 (F) also stated; *"Oh yes! I have issues like having frequent headaches, and digestive issues, that I believe are linked to the ongoing stress and lack of sleep and burden of parenting."* P3 (F)

Code: Physical Exhaustion and Weight

Parents commonly noted the physical tiredness and weight-related challenges they faced. Many parents reported feeling physically weary from caring for a child with autism spectrum disorder. This weariness was generally caused by managing the child's everyday demands, such as treatments, appointments, and emotional support. Some parents expressed weight-related concerns, including obesity. Caregiving-related stress and time constraints can lead to bad eating habits, a lack of exercise, or inconsistent sleep patterns, all of which contribute to weight increase and obesity in some parents. According to P5 (F); *"I've also experienced digestive issues, which I believe are linked to stress. It's a lot to manage, and my physical health has certainly been affected. Obesity is increasing due to not keeping self-care or the care for the body weight."* P5 (F), P9 (M) also added; *The constant stress has also led to frequent headaches and a few bouts of illness that I believe are linked to my stress levels. My energy levels are often low, and I feel physically exhausted a lot of the time"* P9 (M)

Figure 6: Concept Map of Multifaceted issues



Note. The above figure illustrates in details the superordinate and subordinate themes which are the multifaceted issues the parents face while having or raising a child with ASD.

Figure 7: Word Cloud for Multifaceted issues



Note. The above figure illustrates the word cloud for the multifaceted issues the parents face

DISCUSSION

Pakistani parents who care for autistic children are highly vulnerable to anxiety and depression and mood disorders due to significant stress. The fact that those parents cannot offer any form of emotional assistance because of this condition may affect the stability of families. It can be challenging to manage an autistic child; societal prejudice also accompanies this condition. As, 40% of Pakistani households, according to Aftab et al. (2023), had markedly elevated levels of symptoms related to depression from all over the world. Such observations are supported by global studies; for example, on the same note, Alibekova et al. (2022) concluded that similar groups from different countries narrated such stories, indicating it as a worldwide problem.

Knowing your child has autism can greatly affect your emotions and overall mental health. Parents may have difficulty accepting their child's diagnosis because mental health problems are often stigmatized within society. This is something many people feel embarrassed or helpless about (Nawaz et al., 2021). This finding does not only apply in one culture; Oduyemi et al. (2021) stated that it is a painful experience for parents across cultures when they realize that their son or daughter has autism spectrum disorder. Such a predicament is worsened in Pakistan by cultural shame, hence necessitating campaigns for awareness and culturally sensitive mental health services.

The social isolation of mothers because of cultural practices may confine them to their homes (Gómez-Campos et al., 2023). In turn, this can cause depression and make them feel lonely. Community support groups that can help address these problems and increase social interactions should be created. Catalano et al. (2018) cite previous studies undertaken in the West that indicate the importance of supportive networks for promoting good parental mental health. It is therefore imperative that community support be extended to all families with children diagnosed with autism.

As evidenced Asghar et al. (2023), Pakistani society often disapproves of and judges' parents who have children with autism in Pakistan. This may make their situation worse by discouraging medical attention-seeking as well as school enrollment among them. The best approach to reducing stereotypes and facilitating integration is through public awareness campaigns and education. According to Turnock et al. (2022), global public awareness plays a major role in combating stigma, especially across various cultures.

Many parents are afraid of being stigmatized or criticized when they go out in public, leading to loneliness aggravation as well as mental health problems (Ramzan et al., 2022). Safe environments for open sharing among parents as caregivers would allow fewer avoidance coping mechanisms, thereby driving down the occurrence of such cases. A worldwide study highlighted by Turnock et al. (2022) indicates that transparent conversation and the elimination of shame can prevent social avoidance.

Many parents find it difficult to balance work with family responsibilities. Work-related challenges in the Pakistani labor market include rigid work schedules, limited parental leave, and unfriendly working environments (Furrukh & Anjum, 2020). The consequence is a decrease in employee attendance and productivity. This implies that there is a need to establish a balance between professional and personal life by making policies that encourage parents to perform their childcare duties. According to Befkadu et al. (2022), such policies enhance wellbeing and are consistent with previous research findings.

STUDY LIMITATIONS

This study has various limitations that might reduce the generalizability of its findings. Firstly, the sample size is small, only 12 participants (6=male and 6=female) limits the capacity to generalize the findings to the entire population. Further The study also did not explore the children's various degrees of severity of ASD, which may have an impact on their parents' experiences.

STUDY IMPLICATIONS

Grounded in ecological system theory, this study underlines how different interconnected systems, from immediate surroundings to broader societal contexts, influence parents' experiences. This study also emphasizes the need for required policies that refer to the unique need of parents having a child with ASD.

FUTURE SUGGESTIONS

To improve the generalizability, future research should comprise a larger sample size of parents from a diverse range of backgrounds.

CONCLUSION

This study explored the experiences of the parents who were having or raising a child or children with autism spectrum disorder, the focus was on the multifaceted issues the parents face while raising a child with autism spectrum disorder. It has been explored that the parents were having different issues, and those issues were categorized into themes such as, psychological issues, Social Issues, Health related issues, Occupational or work related issues.

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