

Challenges Faced by Parents of Children with Autism in Gilgit-Baltistan: A Comprehensive Analysis

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Abstract

This study explored the multifaceted challenges faced by parents of children with Autism Spectrum Disorder (ASD) in Gilgit-Baltistan. Using a quantitative research design and structured questionnaires, data were collected from 50 parents (21 fathers and 29 mothers) to analyze social, emotional, financial, and family-related difficulties. Results revealed that stigma, social isolation, and misconceptions about autism, such as beliefs linking it to poor parenting or supernatural causes, remain widespread, leading to judgment and exclusion within communities. Emotionally, parents reported high stress, anxiety, and sadness due to caregiving demands and lack of professional mental health services. Financially, the cost of therapies, medical care, and travel to distant treatment centers imposed severe economic burdens. Family life was also affected, with mothers assuming most caregiving responsibilities, creating marital tension and emotional distance, while siblings often felt neglected. The findings highlight the urgent need for community awareness, professional training, and institutional support to promote inclusion, relieve parental stress, and strengthen family well-being.

Keywords: Autism Spectrum Disorder (ASD), parental challenges, social stigma, emotional stress, financial burden, family dynamics, Gilgit-Baltistan, inclusion, mental health support, community awareness

Introduction:

Parents in Gilgit-Baltistan have a hard time raising a child with autism, as child-rearing incurs numerous emotional, financial, and social difficulties. Most of them are highly stressed, anxious and depressed because of doubts about the future of their child and absence of psychological and professional care. The daily chores of the caregivers can create stress between the family members that result in lack of time to be with other children and conflicts between a husband and a wife. The parents also experience social isolation and tend to be judged by others, which aggravates their state of emotions (Khaliq, Dr. Muhammad, Haider, and Wajeaha, 2025). These struggles are compounded by financial pressure since medical care, therapy, and educational provision of children with autism are expensive. The burden is aggravated in rural locations including Gilgit-Baltistan where access to specialized facilities and professionally trained personnel is limited (Amanda, Charlotte, and Poul)

The situation is also complicated by cultural stigma. The perception many individuals have regarding autism is that it is the consequence of poor parenting or supernatural intervention hence delayed diagnosis and lack of proper care. The mothers especially get blamed and socially excluded. In the face of these, there are parents who maintain their faith, community and champion the rights of their children. However, studies point out that the early intervention and sensitization efforts can improve the developmental aspects as well as family welfare (Fatima, Tehreem, and Aisha). Aggression, repetitive behavior, and any behavior that cannot be predicted are some of the key stressors among parents. The smallest everyday alterations may lead to a meltdown, so life becomes difficult on the daily basis. Parents do not want to socialize because they are afraid of embarrassing others in society, which makes them more isolated and lessen chances of children developing socially.

It is also very expensive financially, because the cost of raising an autistic child is nearly three times of raising a typical child. Parents are forced to quit jobs to attend to children, which means losing income and having a low economic security in the long run. Some of them do not have early interventions and professional advice, as they do not feel ready to deal with behavioral problems. Parents are unable to find a balance between therapy, home routines and care giving duties without the presence of regular strategies or community support. Lack of government or institutional support exposes the families to personal resilience and informal networks (John & Philipes, 2023).

Parents emphasized the need to have organized schedules and learning how to react to problematic behavior in a calm manner. The identification of triggers and the development of predictable schedules contributed to the minimization of meltdowns and emotional stability. Other parents used support groups, which helped in relieving their emotional burden, exchange experiences, and coping skills. Social exposure through gradual exposure to social situations allowed reducing the isolation of children, as well as improving their social skills. Despite the lack of formal support, therapy and cooperation with teachers and medical workers were useful. Finally, the external support facilities like the financial assistance, the community resources, and respite care were regarded as the factors that help to alleviate the stress that caregivers have and ensure more favorable outcomes of the children and their families (John and Philipes, 2023).

Statement of the Problem

Parents of children with Autism Spectrum Disorder (ASD) experience many difficulties which influence their lives a lot in Gilgit-Baltistan. Such challenges are not exclusive to emotional stress, but also affect financial and social problems. There is the stigma attached to autism resulting in isolation in the society where mothers are the greatest victims as they are blamed or judged. Also, the area does not have sufficient services, qualified specialists, and special facilities that can help families with ASD diagnoses and treatment. Therefore, the parents lack access to resources as compared to the bigger cities. Although studies have been done in other regions of Pakistan, the experiences of parents in Gilgit-Baltistan have little knowledge. The absence of local data forces families to live with their hardships and policies are either too weak or inapplicable to their situation. To create more effective support systems and policies it is necessary to conduct proper research about the specific challenges that these families have to overcome.

Research Objectives

1. To examine the social challenges encountered by parents raising children with autism.
2. To analyze the emotional difficulties experienced by parents of children with autism.
3. To explore the financial and occupational constraints faced by families in the care and upbringing of a child with autism.
4. To investigate the impact of autism on overall family dynamics, including relationships among parents, siblings, and extended family members.

Literature Review

Parents of children, who have Autism Spectrum Disorder (ASD) in Gilgit-Baltistan experience highly

entrenched social, emotional, financial, and family issues that impact on their overall well-being and quality of life. These parents are faced with a lot of stigma and miscomprehension in their society. Families in communities where autism is perceived as a curse or punishment of the supernatural nature tend to be blamed and excluded. This kind of misconception drives social isolation because the neighbors and the extended families might misunderstand the actions and additional behaviors of the child such as repetitive behaviors or the absence of communication skills as a reflection of bad parenting. This stigma makes parents unwilling to obtain professional assistance or even attend community activities which makes them hide the status of their child in fear of being judged. This social exclusion is further enhanced by the lack of awareness programs and structured support systems. The research in Pakistan shows that the false beliefs about autism are some of the factors that lead to poor access to social resources and lack of engagement with the community (Fatima, Tehreem, and Aisha, 2023; Khaliq, Muhammad, Haider, and Wajeeha, 2025). These families are isolated, and this fact mirrors the situation that has been occurring in a wider society, where historical beliefs and cultural taboos have prevailed over scientific comprehension of developmental disorders. Therefore, parents, in this case, mothers are burdened with another social responsibility of being care givers and at the same time providing protection to the reputation of the family in a society that judges.

Raising an autistic child in Gilgit-Baltistan is a psychological battle of a lifetime, emotionally. Parents have feelings of grief, anxiety and guilt getting used to the inconsistency of child behaviors such as tantrums, aggression and communication problems. Hall and Graff (2011) mention that the emotional burden of autism caregiving belongs both to the challenges of behavior of a child as well as to the lack of support structures. This causes parents to be stressed internally due to the absence of available counseling or therapy services. The rate of emotional exhaustion is witnessed to be higher among mothers than fathers since they are the main caregivers (Griffith and Hastings, 2010).

Achieving this gendered inequality is based on the cultural expectations that confine care giving and household roles to women only, with the male being considered as a breadwinner. This disparity over time leads to emotional exhaustion and helplessness by mothers. Gilgit-Baltistan is a conservative social environment, where emotional distress is not a topic of conversation, which contributes to additional isolation. Woodgate, Ateah, and Secco (2008) note that parents of autistic children often experience a sense of social invisibility, in which their plight is not recognized, which puts them in a state of living in a stress and feeling lonely. The lack of mental health infrastructure in the area and emotional burnout leads to chronic anxiety and depression in a number of parents who feel they are unready to handle the difficulties of autism without professional assistance.

The economic aspect of rearing a child with autism presents an extreme strain to the families in Gilgit-Baltistan. Parents claim significant costs of therapies, the healthcare system and special education, which may not be local. The high cost of transportation and accommodation often makes many people have to go to big cities like Islamabad or Lahore to be properly diagnosed and treated (John and Philip, 2023). Families with limited income have impossible decisions to make - either skipping therapy sessions or selling property to pay treatment. The assistance of the government or NGO is minimal, so parents have to rely on personal savings or community support within their neighborhoods. Mick Tilford et al (2015) highlight that the cost of raising a child with autism is almost three times higher than the cost of raising a neurotypical child. These expenses are catastrophic to low-income families who rely on agriculture or manual labor. Mothers usually have to quit their work to take care of their families full-time, and this further worsens family income. The financial pressure thus created adds emotional stress and increases poverty. Barbara S. Saunders et al. (2015) have discovered that financial instability in autism caregivers tends to decrease access to health care, infrequent therapy, and economic insecurity. In Gilgit-Baltistan, with limited institutional support, the issue of financial hardship turns out to be one of the most chronic ones faced by parents, as it does not only affect their capacity to manage the needs of their child but the stability of the family unit in general.

Family relationships and domestic life are also redefined by autism. The daily stress of being the caregiver usually puts a strain on the marriage, as partners are not able to withstand stress and fatigue,

as well as differences in emotional reactions to the conditions of their child. Mothers are expected to play most of the caregiving roles whereas fathers following the traditional gender roles contribute more in terms of finances. Such unequal division of labor may cause emotional distance between the spouses and restrict the participation of fathers in the process of child development. According to a study conducted by Dr. Najati, Dr. Nawaf, Dr. Moayyad, and Dr. Mu'tasem (2020), in the event of father disengagement, marital satisfaction and child outcomes decrease. Siblings are also impacted by the existence of an autistic child who may feel neglected because of the unfair attention towards the sister or brother. Such children can be jealous or confused especially when parents have to attend to behavioral therapy or therapy sessions as opposed to spending time with their families. Additionally, the extended family members are mostly not understanding of autism, which results in conflict and additional emotional isolation. The stigma associated with autism may result in internal family separations in a society where the reputation of the family is highly valued, as in the case of Gilgit-Baltistan.

Parenting a child with autism in Gilgit-Baltistan can be seen as a source of social isolation, emotional stress, and poverty supported by cultural misunderstandings and inadequate institutionalization. These factors interact and influence the stability and social functioning of the families as well as the mental health of the parents. To overcome such multidimensional challenges, researchers and practitioners propose the development of special centers, therapy programs, financial aid, and awareness programs to decrease stigma. It is also important to develop inclusive educational opportunities and educate medical workers to diagnose and assist children with autism. The cumulative burden experienced by parents can be reduced through increased awareness and institutional support in the society to enable the parents work through autism with dignity, resilience and hope of a better future.

Research Methodology

The research design is quantitative and it utilized a structured questionnaire to explore the Challenges Faced by Parents of Children with Autism in Gilgit-Baltistan. The tool contained Likert scale questions addressing four major domains: social, emotional, financial, and family-related issues. A Purposive sampling method was used to sample out 50 parents (21 fathers, 29 mothers) of children with autism in the District of Gilgit so as to have a varied representation. The data was obtained via self-administered questionnaires in special and inclusive education centers. An expert in the Department of Special Education validated the questionnaire to ensure that the content is accurate and relevant. Ethical standards were observed- the participants were made aware of the purpose of the study, guaranteed confidentiality and informed consent was given. The researchers followed institutional ethical standards to enable integrity, respect, and safeguarding of the rights of participants.

Analysis and Results

Table 1. Demographic Characteristics of Respondents (N = 50)

Variable	Category	Frequency	Percentage (%)
Gender	Male	21	42.0
	Female	29	58.0
Age	25–30 years	11	22.0
	31–35 years	12	24.0
	36–40 years	15	30.0
	41–45 years	12	24.0
Education Level	None	8	16.0
	Primary	4	8.0
	Secondary	13	26.0
	Bachelor	14	28.0

Variable	Category	Frequency	Percentage (%)
Monthly Income	Master	11	22.0
	25,000 and below	6	12.0
	25,001–50,000	9	18.0
	50,001–75,000	15	30.0
	75,001–100,000	12	24.0
	Above 100,000	8	16.0
Place of Residence	Urban area	21	42.0
	Rural or remote village	29	58.0
Child's Age with Autism	2–4 years	15	30.0
	5–9 years	22	44.0
	10–14 years	12	24.0
	15 years and above	1	2.0
Distance to Autism-Related Services (in km)	5–10 km	17	34.0
	11–15 km	8	16.0
	16–20 km	9	18.0
	21–25 km	11	22.0
	Above 25 km	5	10.0

Table 1 presents the demographic data, which show that the vast majority of respondents were females (58%), who lived in rural or remote locations (58%). Most of the respondents were aged 31–40 years (54%), and a significant number had at least a bachelor's degree (28%), or master's degree (22%). In terms of income, 30% of the respondents earned between 50,001–75,000 PKR per month implying that there was a representation of middle-income income group. The majority of children with autism were 5–9 years old (44 percent), and a smaller percentage was over 15 years (2 percent). Regarding accessibility, 34 percent of the respondents resided within the 5–10 km of autism-related services, with 10 percent having to travel more than 25 km, indicating a possible discrepancy in service provision to those living more distant.

Table 2. Descriptive Statistics of Social Challenges Faced by Parents of Children with Autism (N = 50)

Statement	Mean	Std. Deviation
Parents of autistic children in my community face social isolation due to a lack of understanding about autism	2.88	1.14
People in my community believe that autism is caused by bad parenting or supernatural forces	2.92	1.56
Families of autistic children are often excluded from social gatherings and events	3.02	1.08
I feel judged by others because of my child's autism-related behaviors	3.02	1.33
Many parents of autistic children prefer not to disclose their child's condition due to fear of judgment	3.24	1.44

In Table 2, the findings show that the strongest social issue facing the parents of children with autism in Gilgit-Baltistan is the unwillingness to share the diagnosis of a child with autism out of the fear of being judged ($M = 3.24$, $SD = 1.44$). This is an indication of high degree of stigma and self-censorship within the society. Immediately after this, parents said that exclusion in social gatherings and the feeling of being judged by others had a mean of 3.02, which is a moderate level of agreement with these experiences. At the same time, views about autism as caused by bad parents or supernatural powers ($M = 2.92$, $SD = 1.56$) and the social isolation ($M = 2.88$, $SD = 1.14$) demonstrate a bit smaller, yet significant, levels of agreement. When combined, the implications of these results are a pattern of social exclusion, stigma, and judgment of parents of children with autism in this area- several measures like community-based awareness, social support networks, and culturally sensitive interventions can be recommended to reduce barriers and enhance the well-being of parents.

Table 3. Descriptive Statistics of Emotional Challenges Faced by Parents of Children with Autism (N = 50)

Statement	Mean	Std. Deviation
Raising an autistic child causes me constant emotional stress and exhaustion.	2.94	1.50
I often feel helpless when I cannot manage my child's challenging behaviors.	2.66	1.39
The emotional toll of caring for an autistic child often leads to feelings of anxiety and sadness.	3.10	1.37
The lack of mental health services in my community exacerbates emotional stress.	3.16	1.36
I sometimes feel overwhelmed and disconnected due to the constant caregiving demands.	2.96	1.34

Table 3 illustrates that parents of children with autism in Gilgit-Baltistan undergo significant emotional stress. The largest mean value ($M = 3.16$) shows that the absence of mental health services is one of the factors that leads to their emotional stress. Demands of caregiving ($M = 3.10$) also led to feelings of anxiety and sadness. Constant emotional exhaustion ($M = 2.94$) and feeling overwhelmed or disconnected ($M = 2.96$) had moderate levels of agreement. Feeling helpless in handling difficult behaviors was the lowest mean ($M = 2.66$) so that although emotional stress is common, there are some parents who have developed coping strategies. In general, these results suggest that emotional support programs and easy access to mental health services in the area are urgently needed by parents.

Table 4. Descriptive Statistics of Financial Challenges Faced by Parents of Children with Autism (N = 50)

Statement	Mean	Std. Deviation
The financial costs of caring for an autistic child are overwhelming.	2.72	1.46
My family struggles to afford specialized therapies and treatments for my child.	3.26	1.44
Frequent travel for diagnosis and therapy puts an additional financial strain on our family.	3.18	1.40
We receive little or no government financial support to help with autism-related costs.	2.92	1.29
The lack of local therapy centers increases the financial burden due to travel costs.	3.00	1.46

Table 4 indicated that one of the significant concerns of parents of children with autism in Gilgit-Baltistan is financial issues. The largest mean ($M = 3.26$) shows that most families are not able to afford special therapies and treatment whereas most families are forced to travel frequently to get diagnosed and treated ($M = 3.18$), further providing financial strain. Lack of local therapy centers ($M = 3.00$) and lack of government support ($M = 2.92$) showed moderate agreement. The outcomes of these studies emphasize the existence of an urgent demand in the area to provide affordable and accessible autism services and financial support programs.

Table 5. Descriptive Statistics of Family-Related Challenges Faced by Parents of Children with Autism (N = 50)

Statement	Mean	Std. Deviation
The emotional strain of raising an autistic child negatively impacts my marital relationship.	3.00	1.36
Mothers are typically expected to take on the majority of caregiving responsibilities, leading to gender-based tension in families.	2.88	1.32
Fathers' limited involvement in caregiving creates emotional distance between them and the child.	2.78	1.46
Siblings of autistic children often feel neglected due to the focus on the child with autism.	3.20	1.53
Extended family members misunderstand the child's behaviors, leading to family conflict.	2.94	1.41

Table 5 reveals that parents in Gilgit-Baltistan face numerous family-related problems when bringing up a child with autism. The largest mean ($M = 3.20$) suggests that caregiving demands are more or less emotional and affect family relationships in that siblings tend to feel neglected. Other concerns were marital strain ($M = 3.00$) and family misunderstandings ($M = 2.94$). At the same time, gender-based caregiving strain ($M = 2.88$) and low paternal engagement ($M = 2.78$) also emphasize the disparities in caregiving between parents and children. The results highlight the importance of providing family counseling and support services that are inclusive of the whole family to enhance family relationships and minimize stress associated with care giving.

Summary

The research article entitled "Challenges Faced by Parents of Children with Autism in Gilgit-Baltistan: A Comprehensive Analysis" was a study focused on the complex set of problems faced by parents who have children with autism in the area. Results indicated that parents have four principal categories of challenges social, emotional, financial, and family-related. Socially, parents cited stigma, judgment, and alienation by the community based on the common misperceptions about the disorder, including the belief that it is a consequence of bad parenting or super nature. On the emotional front, most parents felt much stressed, anxious, and depressed, which was exacerbated by the absence of mental health care and professional support. Economically, the burden of treatments, healthcare services and travelling long distances to far hospitals was very demanding to families especially those living in rural areas with little access to special care.

There was also an adverse effect on family dynamics. The primary caregiving role was played by mothers, which resulted in the tension of the genders and the lack of communication between spouses, and siblings were often neglected due to the attention which was paid to the autistic child. Nevertheless, there were instances when parents were resilient because of faith, routine programs, and support networks. The paper highlights the necessity to implement the policy intervention, awareness and affordable therapeutic services, and family counseling in Gilgit-Baltistan. The solution of these

gaps can decrease stress among parents, increase their social integration, and improve the quality of life of families with autistic parents.

Discussions

The results of the study give a clear picture of various and interconnected issues, as parents bring up children with autism in Gilgit-Baltistan. The findings indicate clearly that the parents have considerable emotional, financial, social, and family-related burdens affecting their well-being and the overall stability of the family. In line with the works by Hall & Graff (2011) and Griffith & Hastings (2010), the emotional distress was among the most urgent challenges as most of the parents mentioned that they always felt anxious, exhausted, and sad because of the caregiving burden and the lack of any psychological support. This distress is exacerbated by the scarcity of counseling or therapy services in Gilgit-Baltistan, so parents have to cope with complex behavioral problems without the help of a professional. Cultural taboos which prevent a free conversation about mental health also contribute to the emotional strain where the parents, especially the mothers, take it to themselves and end up suffering in silence.

Another key issue was the financial burden, which resonated with the results of Saunders et al., (2015) and John & Philip (2023) as they also reported that families of children with autism incurred expenses that are almost three times the expense of neurotypical families. According to this study, parents cited that they are financially strained because of the high costs of treatments, doctor visits and special education as well as the everyday travelling to remote cities to seek appropriate treatment. There is no government assistance or a local therapy center, which compels the family to use personal funds or informal support, adding to the economic instability in the long term. Equally, the research observed that social stigma is still entrenched in the local culture, and autism is commonly misconstrued as a supernatural or parental failure. It results in exclusion of the community, late diagnosis, and unwillingness of parents to obtain professional assistance- findings that are consistent with Fatima et al., (2023).

Family issues were also identified as a significant problem, and the role of a caregiver was frequently disproportionately assigned to mothers, which caused marital stress and emotional separation. This confirms the findings by Najati et al., (2020), who reported that unequal care giving roles undermine family cohesion and cause psychological stress. Even siblings were documented to experience a sense of being neglected and even distant relatives failed to understand the state of the child leading to conflicts and isolation. These consequences emphasize that autism has not only an impact on the child alone but equally the family unit. The discussion thus highlights the need to undertake comprehensive interventions beyond clinical care. Stigmatization needs to be counteracted through awareness and specialized centers need to be set up in Gilgit-Baltistan to offer convenient therapies and counseling. Financial assistance by governments, local parent groups and family counseling programs might be used to reduce the psychological and economic stress and inclusion and emotional strength among families of autistic children.

Findings

The analysis revealed some important results demonstrating the urgent problems of parents of children with autism in Gilgit-Baltistan. The findings have shown that social stigmatization and ignorance are some of the most pressing issues. Most of the community members are still viewing autism in terms of superstition or faults with many still linking it to bad parenting or spiritual factors. This myth contributes to social exclusion, stigmatization, and lack of willingness among parents to reveal the status of their child that hinders access to early intervention and community support. Thus, there is an evident necessity to advance the awareness and educate people about autism by means of awareness campaigns, inclusive education and culturally suitable information programs.

The emotional results showed that parents experience a high degree of psychological stress, anxiety, and fatigue as they are subjected to the caregiving demands that are always present and lack professional mental health care. Parents, especially mothers, also reported higher emotional strain

because most of the caregiving burden falls on them demonstrating gender inequality in parental roles. Economically, the research discovered that families have a dire economic impact, since special therapies, traveling to receive therapy, and medical expenses are unaffordable to numerous families. This economic stress is further compounded by the fact that there is no government support or rehabilitation facilities within the area. Family dynamics were not good either, siblings usually lived feeling neglected, and marital tension was frequent related to unequal caregiving responsibilities and emotional burnout.

To address these issues, the research points to the necessity to open special centers on autism in Gilgit-Baltistan, which would provide quality therapy, counseling, and training to parents at a low cost. These families should be considered economically and psychologically to facilitate with government funding and NGO partnerships. In addition, stigma can be minimized through policy frameworks and training of teachers, as well as sensitizing communities, which will foster acceptance. Altogether, to make the life of children with autism and their parents in Gilgit-Baltistan better, the access to services, the professional capacity, and the support of family systems are necessary steps to be taken.

Recommendations

1. Create Special Autism Centers:

To decrease the burden on the families in terms of travel and finance, the government should establish regional autism centers that provide diagnostic, therapeutic, and counseling services.

2. Encourage Community Awareness Programs:

Misunderstandings about autism and stigmatization across communities should be removed through the initiation of culturally sensitive awareness programs.

3. Grant Financial aid:

Children with autism should be given subsidized treatment and sponsored programs of financial aid provided by the government to low-income families to take care of the child.

4. Improve Psychiatric Care:

Psychological counseling and parental support groups should be made accessible so that caregivers can be able to cope with the stress and emotional burn out.

5. Promote Inclusion in Education:

Educational establishments are supposed to practice inclusivity, educate teachers in special education, and offer personalized learning programmes to students with autism.

6. Support Family Counseling:

Gender-based tension can be reduced by offering programs that encourage the distribution of child-care duties between parents and contribute to a stronger relationship within a family.

7. NGO and Community Cooperation:

Collaborations between local NGOs, healthcare facilities, and community leaders will be beneficial to increase the service reach and sustainably support those families affected.

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