



RESEARCH PAPER

Socio- Psychological Challenges Faced by the Parents of Children with Autism Spectrum Disorder: A Cross-Sectional Study in Rawalpindi and Islamabad

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ABSTRACT

Autism spectrum disorder is a chronic neurodevelopmental disease in children characterized by significant impairments in communication, social interaction, cognitive function, and sensory processing. These deficiencies substantially affect their daily lives, resulting in difficulties for their parents. Research on the socio-psychological issues faced by Pakistani parents of children with ASD is limited. This study aims to document the socio-psychological difficulties of parents with autistic children to enhance awareness, provide insights, and offer feedback to healthcare professionals and other members of society. This study was quantitative in nature. A cross sectional survey was conducted in the federal capital area of Islamabad and the district of Rawalpindi. The researchers approached parents of autistic children at various autism rehabilitation centers and hospitals located in the Twin Cities. A total of 201 fathers or mothers participated in this study. Findings indicate that parents suffered from stress and disruptions in family life. Their children with ASD also experienced discrimination in their familial and communal lives. Most parents felt ashamed when they diagnosed their child as autistic. This is due to the societal stigma associated with autism. Based on these findings, this study recommends to conduct public awareness campaigns and establish formal support networks to enhance parental empowerment by easing their socio-psychological challenges.

KEYWORDS Autism, Children, Challenges, Pakistan

Introduction

Autism spectrum disorder (ASD) is a persistent neurodevelopmental condition frequently observed in children, characterized by various impairments (Imran & Azeem, 2014). ASD is diagnosed by communication difficulties, social withdrawal, aggressive behaviours, poor eye contact, obstinacy, insensitivity, hypersensitivity, and other behavioural anomalies in children's daily activities (Sivberg, 2002). Additional atypical behaviours associated with children diagnosed with ASD include self-injurious actions, sleep disturbances, heightened pain sensitivity, irregular eating patterns, excessive fear, and stubbornness (Widiger & Samuel, 2005).

ASD affects around 75 million individuals globally, representing 1% of the population. In 2021, it was estimated that 1 in 100 children were diagnosed with ASD, indicating a notable increase in its prevalence. Since 2000, the prevalence of autism has risen by 178% (The Treetop, 2024). The prevalence of autism spectrum disorder (ASD) in South Asia varies, with rates reported at 0.09% in India and 1.07% in Sri Lanka (Hussein, 2011). This estimate suggests that one in 93 children in this region is affected by ASD. Conversely, reliable data regarding the prevalence of ASD in Pakistan is unavailable (Asghar et al., 2023). There is no reliable data available regarding the prevalence of ASD in Pakistan (Akhter et al., 2018). A study involving a cluster sample of 6,365 children revealed that 6.5%

exhibited mild mental retardation, while 1.9% were identified with severe cognitive disability (Bashir et al., 2002). An estimate of 19.0/1,000 children experiencing mental retardation or learning disabilities was also noted in Karachi (Durkin et al., 1998). According to a study conducted by Mubbashar and Saeed in 2001, nearly 16 out of every 1,000 children aged 3 to 9 experience severe mental retardation. Morton et al. observed that Pakistani children exhibited a slightly elevated prevalence of autism (2.57/1,000) and cerebral palsy, in addition to higher rates of severe learning difficulties, as well as hearing and vision issues (Morton et al. 2002). One might hypothesize that the prevalence of autism could also be considerably elevated, considering the studies conducted on mental retardation and cognitive disability (Imran & Azeem, 2014).

The prevalence of ASD in Pakistan has primarily been studied in hospital settings or among children with autism in special schools, making it challenging to generalize the findings to broader contexts (Hussein, 2011). Hussein et al. (2011) observed that the prevalence of emotional and behavioural problems in children aged 5–11 years studying schools in Karachi is around 17%, the highest in the developing world. Recently, the Pakistan Autism Society estimated that approximately 350,000 children in the country were living with ASD as of 2020 (Khalid et al., 2020).

A deeper understanding of parents' experiences in raising a child with ASD is essential, as many remain unaware of these experiences. In societies like ours, most people do not focus on the child diagnosed with ASD and also neglect the challenges faced by their parents, siblings, and extended family members. This study aims to document the socio-psychological difficulties of parents with autistic children to enhance awareness, provide insights, and offer feedback to healthcare professionals and other members of society. This study is imperative to sensitize people about the challenges that parents of children with ASD face in their daily lives.

Literature Review

The dearth of academically published research from Pakistan presents significant challenges in quantifying the burden of ASD. Early diagnosis of a child with ASD is critical, as early intervention has demonstrated positive effects on outcomes for individuals with neurodevelopmental disorders like ASD (Fujiwara et al., 2011). Findings indicate that initiating early intervention for children with ASD between the ages of two and three can lead to a notable reduction in their symptoms (Eikeseth et al., 2009). This also positively influences a child's future functioning (Richards et al., 2016). The enhancement of children's communication, socialization, and behaviour is evident with early intervention services (Chaabane et al., 2009). Studies have indicated that failing to intervene early and appropriately can lead to long-term difficulties (Matson et al., 2009).

There is a notable lack of awareness and knowledge regarding ASD in Pakistan (Anwar et al., 2018). A recent investigation into the experiences of Pakistani mothers with children diagnosed with ASD revealed that 5 out of 15 participants were unfamiliar with the term "autism" before their child's diagnosis (Furrukh & Anjum, 2020). Upon receiving an ASD diagnosis, parents typically encounter a range of emotions, such as grief and loss, anxiety regarding the long-term implications of the diagnosis, a sense of mourning for the life experiences their child may miss, and, for some, a response comparable to experiencing a death in the family (DeGrace et al., 2014). Caring for children with ASD presents significant challenges due to their difficulties in communicating needs (Peppé et al., 2007) and their tendency to become distressed when routines are disrupted (Werner DeGrace, 2004). Global research has linked caring for ASD children with deteriorating mental health among parents (Martin et al., 2020).

Marital relationships are put through extreme strain when caring for a child with ASD. This pressure significantly changes the relationship between spouses (Hock et al.,

2012). Rearing an ASD child can create complexities in personal relationships and is linked to higher divorce rates (Karst & Van Hecke, 2012). On the other hand, several parents have indicated that their relationship has strengthened after surmounting the hurdles associated with raising children with ASD (Altiere & von Kluge, 2009).

Parents of children with ASD face considerable challenges, including heightened stress related to their child's condition, psychological difficulties, and a decline in overall quality of life and well-being. These parents often exhibit diminished energy levels and signs of depression. Furthermore, a recent review revealed a link between elevated stress levels and young parents of children with ASD. Mothers experience substantially higher stress and lower quality of life than fathers (Enea & Rusu, 2020). Insufficient social support for mothers of children with autism is the primary predictor of mental health issues (Boyd, 2002). Fathers also experience parenting stress, lack of social support, and increased loneliness (Moorthy, 2023). However, studies consistently do not observe differences in parental gender and/or age (Shepherd et al., 2021).

Parents caring for children with ASD may experience limited professional engagement (Smith et al., 2010), leading to financial strain due to reduced family income (Montes & Halterman, 2008). Many mothers of children with ASD, confronted with increased childcare responsibilities and challenging household demands (Courcy & des Rivières-Pigeon, 2021)), are compelled to reduce their work hours or leave their employment. This lowers the family income and increases financial stress (Brien-Bérard & des Rivières-Pigeon, 2018).

Material and Methods

Nature

This study used descriptive research to collect quantitative data. This design was selected to examine the socio-psychological difficulties encountered by parents of children with ASD.

Population

The target population of this study was Parents of autistic children living in the federal capital area of Islamabad and the district of Rawalpindi. Parents of autistic children were approached at different autism rehabilitation centers and hospitals located in these two cities.

Sampling

This study was conducted using simple random technique. The estimated sample size for this 201. Data were collected from 201 mothers or fathers approached at different autism rehabilitation centers and hospitals located in these two cities.

Data collection procedure

Data were collected at autism rehabilitation centers and hospitals. The tool of data collection was a self-administered questionnaire. The first author conducted the data. Parents were briefed about the nature and objectives of the study. Informed consent was taken from them before data collection. Ethical consideration was also taken into account under the approved Ph.D. Board of Advanced Study and Research (BASR) via F. No IIU/2022-Exam-6422.

Analysis

The analysis was performed using descriptive statistics with the Statistical Package for the Social Sciences (SPSS).

Results and Discussion

Table 1
Socio-demographic characteristics of parents having an ASD child

Variables	Frequency (f)	Percentage (%)
Age of the Caregiver (Father or Mother)		
Up to 30 years	64	31.8
31- 50 years	137	68.2
Marital status		
Married	132	65.7
Divorced	59	29.4
Separated	10	5.0
Type of family		
Nuclear	77	38.3
Joint	100	49.8
Extended	24	11.9
Monthly family income (PKR)		
Up to 50,000	57	28.4
51,000 to 100,000	58	28.9
above 100,000	86	42.8
Sex of ASD Child		
Male	146	72.6
Female	55	27.4
Age of the ASD Child		
up to 5 years	84	41.8
6 to 10 years	85	42.3
Above 10 years	32	15.9
Mother education of ASD child.		
Under graduate	41	20.4
Graduate	86	42.8
Post graduate	74	36.8
Father education of ASD child.		
Under graduate	39	19.4
Graduate	76	37.8
Post graduate	86	42.8

More than two-thirds (137, 68%) of the respondents were middle-aged adults who fall in the category of 31-50 years. Less than one-third of the respondents (64, 31.8%) were young adults up to 30 years old. Married individuals comprised nearly two-thirds of the respondents (132, 65.7%). Most of the mothers (86, 42.8%) completed their graduation. Conversely, most of the fathers did (86, 42.8%) post-graduation. This indicates that fathers were more educated than mothers.

The monthly family income data reveals that more than two-fifths (86, 42.8%) of respondents earn over 100 thousand monthly. Fewer than one-third of the respondents (58, 28.9%) reported a monthly family income in the range of 51,000 to 100,000. The results indicate that most respondents had a high economic status. Among the children with ASD, over two-thirds (146, 72.6%) were identified as male. Almost half of the families (100, 49.8%) was living in joint family system.

Table 2
Nature of parenting of ASD child

Nature of parenting of autistic children	F (%)
Caregivers are both parents	158 (78.6)
Caregiver only mother	34 (16.9)
Caregiver only father	9 (4.5)

The findings reveal that over two-thirds of the respondents (158, 78.6%) received care from both parents. Approximately one-fourth of children (44, 21.9%) was getting

caregiving for their mothers. Only, nine fathers reported being responsible for caregiving for their child with ASD.

Table 3
Socio-economic challenges experienced by parents of ASD child

Variables	SA	A	N	D	SD
Financial Autonomy					
I can maintain my financial autonomy to cure my ASD child.	49 (24.4)	83 (41.3)	40 (19.9)	18 (9.0)	11 (5.5)
As a parent, I am dependent on others for economic help to absolve the abnormalities of ASD child.	29 (14.4)	43 (21.4)	46 (22.9)	41 (20.4)	42 (20.9)
Most of the time I have been excluded from different jobs due to having an autistic child.	38 (18.9)	24 (11.9)	32 (15.9)	37 (18.4)	70 (34.8)
I believe that ASD children has disturbed my family life	37 (18.4)	54 (26.9)	54 (26.9)	31 (15.4)	25 (12.4)
Social Alienation and Stigma					
I feel shame (stigma) when acknowledge my children as autistic.	43 (21.4)	45 (22.4)	38 (18.9)	31 (15.4)	44 (21.9)
I feel social alienation due to having autistic children within civic life.	25 (12.4)	52 (25.9)	64 (31.8)	41 (20.4)	19 (9.5)
It is difficult for me to adjust my autistic child with other community's children.	44 (21.9)	54 (26.9)	46 (22.9)	36 (17.9)	21 (10.4)
Family Life Disruptions					
Due to having an autistic child my family disowns me and my children.	27 (13.4)	49 (24.4)	39 (19.4)	38 (18.9)	48 (23.9)
My ASD child face discrimination in family.	34 (16.9)	56 (27.9)	58 (28.9)	28 (13.9)	25 (12.4)
Parental Stress					
I always feel stress of shunning about my autistic child's existence in community activities	31 (15.4)	49 (24.4)	42 (20.9)	36 (17.9)	43 (21.4)
I face emotional behavior problems due to having an ASD child.	24 (11.9)	60 (29.9)	58 (28.9)	42 (20.9)	17 (8.5)
Being a parent of ASD child I mostly bare various questions of poor parenting skills.	37 (18.4)	57 (28.4)	52 (25.9)	30 (14.9)	25 (12.4)

SA =Strongly Agree, A= Agree, N=Neutral, D= Disagree, SD= Strongly Disagree

The majority of the respondents (83, 41.3%) agreed that they would be able to maintain financial autonomy to cure their ASD child. In addition, one-fourth (49.4, 24.4%) of parents strongly agreed on the ability to maintain financial autonomy to cure their ASD child. Findings indicate that the parents of ASD children were not economically dependent on others to manage their children's treatment. The majority of the respondents (70, or 34.8%) showed their disagreement with this belief that they were excluded from different jobs due to having an autistic child. Researchers found that most parents felt ashamed when they diagnosed their child as autistic. They also felt socially alienated within civic life because of having an ASD child. They had problems adjusting their autistic child to other community children.

Regarding disruptions in family life, the majority of parents held the belief that neither they nor their children were disowned by the family. Nonetheless, their child with ASD experienced discrimination within the family context as well. The study indicates that parents of children with ASD encounter significant parental stress in their daily lives. Sixty participants, representing 29.9%, indicated experiencing emotional issues as a result of having a child with ASD. A total of 57 participants (28.4%) reported concerns regarding inadequate parenting skills. Based on these findings, it can be concluded that parents of ASD children face various socio-psychological challenges in their daily life.

Conclusion

The disruption in family life is a common concern for parents of children with ASD. This illustrates the impact of the daily routines and care of children with ASD on family life. Children with ASD face discrimination from family and community. This is because of misunderstandings and lack of awareness about ASD. This occurs in multiple ways, such as being excluded from educational opportunities, having restricted access to inclusive recreational activities, and experiencing social isolation from peers. Furthermore, several parents expressed feelings of stigma and shame upon acknowledging their child's autism. They also feel stress, suggesting that societal attitudes and misunderstandings regarding ASD remain prevalent.

Recommendations

There is a need to conduct public awareness campaigns and establish formal support networks to enhance parental empowerment by easing their socio-psychological challenges. It is essential for these parents to pursue support through groups that facilitate the sharing of experiences and the development of connections that can help them in reducing feelings of isolation. They can also seek counselling. Professional counseling offers essential coping strategies to handle stress and anxiety, while gaining knowledge about autism equips parents to advocate effectively for their child. They can do meditation exercises, listen Holy Quran or offer special prayers to manage their stress levels.

Acknowledgment

This study was the part of doctoral research project submitted by first author at Department of Sociology, International Islamic University Islamabad. The first did this project under the supervision of second author.

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