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The Social & Psychological Burden of Autism: A Phenomenological Study of Autism Moms

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ABSTRACT

Autism moms confront devastating challenges consistently impacting their social, emotional & psychological well-being, still there is insufficient research available on exploring the phenomenon from maternal perspective. To fill the gap, the present study aimed at exploring the lived experiences of autism moms and identifying the psychological & social challenges faced by them. The study employed descriptive phenomenological method by using a qualitative research design to explore the mother's experiences. Fifteen mothers of children with autism were recruited from BMC and Civil Hospital in Quetta, Balochistan, and in-depth interviews were conducted to expose the full spectrum of their experience. Interpretative phenomenological analysis was carried out to analyze transcribed data. The study identified that mothers of children with autism face variety of overlapping problems adversely impacting their personal & social life. The psychological challenges included emotional exhaustion, strain, depression and frustration. Social challenges included stigma, blame, isolation, societal ignorance, and problems in family and spousal relationships. A key theme identified the lack of family & social support to autism moms. The majority of mothers reported receiving minimal societal support insufficient to meet their needs. To reduce stigma and improve the lives of autism moms and their children, public awareness initiatives and stronger social support network are recommended.

Keywords: Autism Moms, Autism Spectrum Disorder, Emotional Burnout, Stigma, Isolation.

Background of the Study

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects people's perceptions, experiences, and interactions with the world over the course of their life. People with ASD feel uncomfortable in social situations while interacting with others and tend to have specific interests or behaviors that they repeat (American

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Psychiatric Association (APA), (2022). Prevalence estimates of autism revealed an increase in measured autism prevalence globally (Zeidan et al., 2022); in 2021 about 1 in 127 persons had autism (*GBD Results*, n.d.). According to the calculation of Pakistan Autism Society, around 350,000 Pakistani children have Autism. Maqbool (2021) revealed that 1 out of every 89 Pakistani children has Autism.

Although some individuals with autism are competent to live self-sufficiently, many require life time assistance and care due to severe disabilities denoted to autism (WHO, 2019) thus, nurturing a child with ASD is a tense and perplexing experience (Falk et al., 2014; Shattnawi et al., 2020) primarily in countries with limited support services. Previous research has established that caregivers of children with autism are inclined to poor mental health, including higher stress, severe anxiety and depression, unhappiness and poorer quality of life compared to those taking care for children developing normally and those with other childhood illnesses (Cohrs & Leslie, 2017). As compared to fathers, mothers experience noticeably elevated stress and poorer quality of life (Enea & Rusu, 2020).

Numerous autism moms stated a sudden increase in childcare responsibilities besides challenging household burdens after their child was diagnosed with ASD (Courcy & Rivières-Pigeon, 2020) ,they were forced to curtail their working hours or even quitting; this eventually led to low family earnings and greater financial stress (Brien-Bérard & Rivières-Pigeon, 2022).

Autism moms face multidimensional challenges extending beyond typical caregiving. Literature has consistently suggested higher stress, anxiety, beside emotional weariness among these mothers, predominantly attributable to the arduous nature of caregiving then inadequate community support and professional assistance (Alibekova et al., 2022; Papadopoulos, 2021). Their emotional distress rises a lot from their child's impulsive behavior, communication hurdles, and insistent uncertainties about their child's future (Neijs et al., 2024).

Social stigma associated with autism also remains a persistent concern as many mother's report being misunderstood or responsible of their child's behavior, resulting in social isolation and withdrawal (Oliver et al., 2024; Rezq et al., 2025). This deficient social understanding shatters mothers' confidence and creates barriers in accessing informal social support crucial to coping and processing emotional distress.

Concerning caregiver burden and quality of life, mothers repeatedly report declined well-being and prolonged exhaustion, due to constant supervision, treatment management, and advocacy responsibilities (Patel et al., 2022). These responsibilities abridged their rest periods, recreation, and limited social interaction, resulting in higher life dissatisfaction (Van Niekerk et al., 2023). Furthermore, studies have frequently reported family and marital stress. Divergent coping mechanisms between couple, collectively with the overwhelming burden of raising an autistic child can result in emotional distance and relationship strain (Papadopoulos et al., 2021).

In Pakistani culture, father has assuming financial responsibility of the family while women are expected to look after the household and children (National Council for Family, 2018) and the changing patterns of household believe that the mothers will control all the long-lasting situations too. In Pakistan the parents of autistic child, especially mothers often feel strain, fear, ashamed, & exhausted. Around 40% of autistic child in Pakistan have sleep issues, which are linked to parents experiencing

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anxiety and having psychological issues (Baig et al., 2021). The cultural practices in Pakistan on Autism may also increase the stress level and affect how parents deal with the situation. Some people in Pakistan view that disability is a penalty. Because of this, families sometimes keep children with disabilities secreted due to feelings of shame and fear of criticism (Rathore et al., 2011). Studies shows that parents who associated autism to supernatural effects after birth, feel upset and confused about it, often see it as a big and lifetime problem (Haney et al., 2018).

Studies have shown that many mothers are left isolated and discriminated against while raising their autistic children, even the close family members and friends assume that the "abnormality" of an autistic child is entirely mother's responsibility in response they contact less and mothers are left with little or no time to be in touch with family and friends. They don't even get enough time for themselves (Acharya & Sharma, 2021; Ji et al., 2023; Papadopoulos, 2021).

Significance

The study focused on filling the research gap in autism experience created by neglecting the maternal perspective by intending for exploring the psychological, emotional and social challenges faced by mothers of children with autism in Balochistan. The study aims at increasing knowledge of autism in Balochistan, to highlight the need of providing crucial help to the local population and to establish stronger autism related policies for entire country.

Objectives of the Study

To explore the psychological, emotional and social challenges faced by mothers of children with autism spectrum disorder.

Research Questions

How psychological difficulties are experienced by mothers of children with autism?
In what way mothers of children with autism spectrum disorder struggle socially?
How does the society treat the mother with an autistic child?

Research methodology

This study applied phenomenological descriptive method rooted in qualitative approach handed-down to interview which describe the shared lived occurrence of individuals to disclose the spirit of specific phenomenon (Creswell, 2014). Two public hospitals of Quetta city (BMC and Civil Hospital in Quetta) were selected for data collection assuming to include participants from diverse social, economic, cultural and ethnic background. By using purposive sampling technique, 15 respondents were recruited contributing to great understanding of the topic. Data was collected by in-depth interviews and was analyzed through thematic analysis.

Findings

Denial & Emotional Distressed following the diagnosis:

Studies suggest that the diagnosis of ASD can be most challenging stage, as mothers may delay early intervention while seeking copious medical opinions for reassurance. Most mothers eventually move from denial to acceptance, which brings solace and

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lets them concentrate on keeping up with their child's development (Gray, 2006; Dale et al., 2006). Most of the study respondents shared that before the clinical diagnosis people around them tried to aware them about their child's condition but they denied.

"Before getting him checked when people told me my child was a bit different, I couldn't believe it. I argued a lot and resisted to admit the possibility that my child might not be "normal".

Most mothers in the present study acknowledged that they didn't accept the reality of their child unless it was confirmed by a doctor and even after the clinical confirmation they found it difficult to accept.

"It was hard for me to believe that my child was autistic, neither did I want to accept it."

The denial was due to the fact that autism is considered a disability and people with autism are regarded as unable to live a full healthy life. Few participants shared that they thought their child had a mystical sickness particularly mothers who had no prior knowledge of autism.

"I took my son to every "pir" and get him treated through "taweez & dam", I believed he will be cured but nothing worked for me or my child."

"my mother-in-law took my son to a pir who told that black magic was causing my child's condition so we gave him money and did whatever he told us to do but there was no improvement in my son so we took him to a local doctor who referred us to a specialist where I first time heard the word "autism".

Such mother with no prior information of autism reacted strongly to the diagnosis as they inferred autism for *"madness, mental illness"*. The severity of emotional distressed followed the diagnosis depended on the awareness level of the mothers in addition to their personal and social lifestyle.

"Our world collapsed when we heard about her disease, in an instant I imagined all the suffering she might go through in her future, and how will she live her life? Who will marry her? What will be her future?"

"In the beginning I used to cry a lot, I was so worried that my chest felt tight all the time"

Denial, crying and emotional distress was experienced by every mother affecting their personal life and mental well-being.

Self-blame & Guilt

Self-blame and guilt are frequently experienced by autism moms due to societal judgment, perceived lack of control, inability to manage household responsibilities and neglecting other children at home.

A mother described that,

"I blame myself, thinking that maybe I didn't care for my child the way he deserved, perhaps by not giving him enough time. I fear I will carry this sense of responsibility for the rest of my life".

As a mother it was not only their concern for their children but they somehow concurred that this disease of their children is their fault. As shared by a respondent,

"It was impossible for me to acknowledge that I have given birth to an "imperfect or

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unhealthy" child."

Another mom talked about her feelings,

"I wondered if I had done something wrong in my pregnancy or when he was little causing his sickness."

The self-blame was amplified when people around them judged mothers or accused them directly or indirectly for their children's behavior. The guilt was also mentioned by many autism moms. On one hand, they felt guilty of not taking sufficient care of their autistic child on the other hand they were unable to manage their household chores properly and take care of or spend time with other children. This guilt resulted in frustration and mental exhaustion for many mothers.

"I do my best to manage it all, but in the end, the stress just keeps building blaming myself for my child's condition, and it makes me feel deeply misunderstood and unfairly judged."

A mothers shared,

"I spend considerable time in taking care and supervising my child that I hardly left any time for my other children; it doesn't only disturb my children but I also feel guilty."

Raising an autistic child while managing chores without any help and having other dependent children is tiring both physically and emotionally. As stated by a mother,

"Taking care of my child with autism is very tiring, I have to keep him close all the time. Although I still manage all the domestic work but I don't get time to play with my children or bond with them emotionally. It feels that because of one child I neglect my other children."

Autistic child usually get attached to one person and become totally dependent on them. In case of mothers; they do not want to share her with anyone else which can be challenging for mothers. As approved by a study respondent,

"If I ever try to involve my other children with us my kid becomes cranky and aggressive, he doesn't know to control his emotions and doctors have advised me to not let her cry so I stop my children and give all attention to her."

Autism moms suffer with severe emotional distress compared to other mothers. They mentioned higher anxiety, depression, besides emotional exhaustion as a result of the continual burdens of caregiving. Their emotional stress is regularly increased because of their child's impulsiveness, their behavior, resulting in persistent concern then frustration. These everyday challenges depressingly influence both their psychological well-being and quality of life (Estes et al., 2013).

Some respondents said that

No one except the mother can justly understand the pain of seeing her child struggle daily. In the beginning, I was distressed and overwhelmed. I sobbed a lot, and watching him would devastate me. But gradually, I accepted that my child is the way he is by God's will. (IDI-1, 3, 4, 10, 12, 13)

Even though I still get worry about how my child's development, I have started to have a strong faith and trust the God.

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Daily Struggles & Emotional Burnout

As a primary caregiver mothers regularly assist the children in their daily routine tasks; these tasks may seem effortless for normal kids but take much longer for children with ASD. It takes much time, patience and energy of mothers which leaves them exhausted both mentally and physically. As mentioned by many study respondents,

"Taking care of my child particularly of her/his hygiene and diet is very stressing…"

Children with ASD often find Activities of Daily Living (ADLs) difficult and depend on their caregivers for their personal maintenance which can be very tiring for their adults especially when mothers have to perform household chores and also have other children. This may result in fatigue as well as mental exhaustion. As established by most of the mothers,

"The doctors have advised me to be gentle with her and avoid hitting her, even though, as you know, it is common in the Brahvi community to discipline children with physical punishment.

"*Managing household chores alone while taking care of my child who requires constant attention and supervision is very difficult, I unintentionally neglect my other children which often leaves me feeling anxious and overwhelmed"*

The study respondent also discussed that comparing their child with other children was also a great stressor but they couldn't help themselves as they mentioned,

"When I see my child's age fellows enjoying their lives fully whereas my child struggling with basic tasks; I feel so stressed"

"It breaks my heart watching other children my child's age learning and performing their personal maintenance tasks, while my child still doesn't understand or experience those things."

Autism moms were suffering from severe mental burnout by prolonged stress due to their child's condition. It not only affected the mothers negatively but also created problems for other family members. The situation was critical in households where less or no motional or instrumental support was offered especially from the husbands. Most of the respondents revealed that fathers were not actively supporting their child with ASD except for providing economic needs.

"*Men often have many responsibilities outside the home, which can leave them exhausted and unable to provide emotional or domestic support."*

"*My husband has his own work and little time to help me in the household chores or take care of our child."*

Spousal support is an important contributor in a woman's life mainly when she is constantly stressed due to the adjustment she has to make daily while taking care of a child who needs continuous supervision and special care. When husbands fail to comfort their wives emotionally or assisting them with household tasks, it leads to a feeling of vulnerability resulting in higher anxiety and depression.

Social stigma

People often misinterpret an autistic child's stimming behavior (motor stimming, vocal stimming, object manipulation) emotional outbursts, or problematic social interaction as indications of neglectful or poor parenting (Gray, 2002).

Many respondents in the present study shared the uncomfortable interaction they

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encounter on daily basis including skeptical stare, perplexed expressions, hurtful comments and insolent opinions. These can be very painful for mothers and heighten their emotional stress. As exhibited by a mother as,

"Anywhere I take my child, people often give him strange looks as if they don't regard him normal, which makes me feel uncomfortable."

Mothers also shared that the uncomfortable encounter was not confined to staring or strange looks but people also pass insensitive remarks, as a mother said,

"Most people pass hurtful comments, saying that my child is mentally disabled and labeling him with various names."

Another respondent added,

"They tell me not to bring him with me in social gatherings because he sometimes hits and disturbs others, I feel uneasy and do not want to go anywhere"

Same experienced was shared by another mom,

"People neither understand sudden changes in my child's behavior nor do they tolerate. They taunt me for not raising my child properly."

Social Withdrawal & Isolation

Another recurring trauma experienced by these mothers was when their children were socially excluded from other parents and were not allowed to play with their children. A respondent shared,

"In family events my own relatives keep distance from both me and my child, they avoid interaction and doesn't even let their children play with mine."

The situation results in social withdrawal and limited social engagement; mothers chose isolation concerning that their child may be mistreated, misunderstood and judged by others.

"I do not feel like going outside with my children because of how people treat us and make us uncomfortable; even my own siblings get irritated and scold my kid without realizing his condition. It often ends in me arguing with them."

The unaccommodating behavior of family members leave mothers feeling isolated forcing them to bear emotional burden without any support leading to a high level of anxiety. A respondent told,

"I have stopped going to my mother's house because my sisters-in-law do not tolerate my kid's tantrum, they fight with me and complain to my brothers so I prefer not going there…. It breaks my heart that my family doesn't stand with me."

Family is the primary source of encouragement and support in hard times but if they fail to accommodate the situation of autism mom; they chose their child's comfort over their relationships and isolate them from people who make their child uncomfortable.

Marital Distress: Spousal Relationship Challenges

Another important impact was experienced in marital relationship. The mothers as primary caregivers were all focused on the child unintentionally neglecting other family members particularly their husbands that negatively affected their relationship. As described by a respondent,

"*In the beginning, our relationship was better, but with an autistic child, managing both my household chores and my personal relationship has become very difficult.*

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The lack of time has overwrought my relationships with husband.
Another respondent shared that,
"Most of my time is spent with my child so I cannot give enough time and attention to my husband which is weakening our relationship."

Spousal support proves to be very effective in life but if autism moms do not get it then they become highly depressed and frustrated.

Discussion

The study focused on autism moms and the impact of raising an autistic child on their psychological well-being and social life. Most of the mothers admitted that raising an autistic child was very challenging; most of their time was spent in taking care and supervising their child which was exhausting both mentally and physically. The study respondents reported that they were left isolated, they stayed at home most of the time and avoided family or social gatherings because they didn't want people to look at their child with pity or pass rude remarks. Similar findings were made by (Abid et al., 2022).

In align with the previous studies (Hamad et al., 2025; Manji & Ghafoor, 2019; Papadopoulos, 2021; Rafi et al, 2024; Ray et al., 2024) mothers interviewed for present study also mentioned that their marital relationship were affected too due to lack of time and insufficient emotional and instrumental support from the husband. This situation worsened the psychological and emotional condition of mothers as the felt depressed and anxious. They were frustrated and challenged without the help and reassurance from family and friends unlike the findings of (Putra, & Badayai, 2025; Magalhães et al., 2021) no study respondent mentioned any support from family or community needed to enable them to manage the burden easily and live a relatively satisfactory life.

Almost every mother discussed about the stigma resulted from the stereotypes attached to autism in our society. According to them their children greatly suffered; people excluded ((Aun et al., 2022) them from social gatherings, made them feel unwelcomed, leaving them (mothers) ashamed and guilty as if their child having ASD was their fault somewhat alike findings were made by (Fowler & O' Connor, 2021).

Future-oriented anxiety was also experienced by every mother, previous studies have also exhibited the feelings of uncertainty and concern about their child's safety, health and social life (Fowler & O' Connor, 2021; Adams, Dadabhay & Neille, 2021; Acharya & Sharma, 2021; Ahmad Badayai et al., 2022). They feared that owing to autism, their children will not be fully accepted by the society besides they won't be able to adapt to the society independently. The constant distress is nerve-wracking and in the absence of a proper support system it affects autism moms to extent that their psychological well-being is negatively impacted and they become irritable worrying themselves sick.

Guilt & self-blame was another major variable described by the study respondents. The guilt autism moms experienced is two folded. Many mothers thought that their child's autism was somehow their own fault, they assumed that by not taking good care of their child in their formative years. The guilt was heightened when people accused them of poor parenting without realizing the child's medical condition same

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findings were made by (Acharya and Sharma., 2021; Bilal, Abbas, & Rafi., 2025; Chung & Ray et al., 2025). On the other hand, they felt guilty of not giving sufficient attention to their other children and neglecting them. According to Adams, Dadabhay & Neille (2021) for mothers treating every child equally was quite challenging in this situation as the child with autism becomes the center of attention and takes all the time, efforts and energy of the mothers leaving them physically exhausted and emotionally drained.

Another major factor contributing to mothers' plight is how people treat their autistic child in social gatherings. The study respondents stated that people often misbehaved with their children, treated them unfairly, labelled them "abnormal" and called them with offensive names these findings second the conclusions derived by (Aslam et al., 2023; Begum et al., 2019; Farrukh & Anjum, 2022; Nadeem et al., 2024; Younesi et al., 2024;). It was revealed by few respondents that they do not take their children for outing or to social gatherings and events because of the fear of people getting uncomfortable around them as reported in previous studies (Achariya et al., 2021; Birhanu, 2021; Nadeem et al., 2024).

Family and friends are primary source of personal strength and backbone of an individual's emotional stability but in case of autism moms they badly failed in providing mothers with strength and emotional support. On contrary, they often made the situation worse with their insensitive behavior. Study participants shared that even their own family members avoid them in social gatherings, keep distance and forbid their kids to play with their child. A body of research has indicated that cultural context can influence the stress experienced by parents of autistic children (Ilias et al., 2017; Kwok, & Wong, 2000) unfortunately in Pakistan mental disorders are still considered a punishment of a sin and this mentality affect people's interaction but when it comes from family or friends it hurts deeply as confirmed from the study respondents.

Recommendations:

Mental health support along with specialized parent training program must be deigned to help out autism moms.

Counseling services for autism moms are essential to manage stress and emotional burnout.

Community awareness programs, social media campaigns must be organized to reduce stigma and stereotypes of autism.

Conclusion

The present research shows that mother as primary caregiver, face crucial social and emotional challenges, often exacerbated by societal blemish. In absence of a support system they are left alone to endure the hardships and manage the challenging takes which adversely affects them. These challenges impact every aspect of autism moms including their psychological well-being, emotional health, marital relations and social life. They often experience anxiety, frustration, isolation, guilt and uncertainty. Mental health support along with specialized parent training program, counseling services, community awareness programs and social media campaigns are regarded essential for autism moms to manage the emotional burnout and to reduce stigma and

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stereotypes of autism.

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