

Through Their Eyes: Exploring the Lived Experiences of Mothers Raising Children with Intellectual Disabilities



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Abstract: *In order to investigate the lived experiences of Pakistani mothers of children with intellectual disability (ID) and to identify their emotional, social, financial, and psychological challenges, this phenomenological study was conducted using Interpretative Phenomenological Analysis (IPA). The participants were selected purposively through non-probability sampling, consisting of five respondents whose ages ranged from 18 to 55 years. The findings revealed themes related to emotional resilience (spiritual coping through the Quran and personal growth), social impact and family dynamics (stigma associated with being perceived as bad parents, threats of divorce, absence of spousal support, and sibling rivalry), emotional challenges (diagnostic shock and denial, chronic anxiety related to dependence on children, and maternal depression and exhaustion), financial issues and resource constraints (high therapy costs compared to low income, career sacrifices, lack of ID services in Pakistan, and barriers to travel to urban areas), and coping strategies and awareness gaps (limited access to NGOs, home-based routines, self-education, cultural myths portraying ID as punishment, and the need for mother-training workshops). These findings addressed all research objectives and questions by highlighting real-life experiences, persistent social and personal struggles, systemic barriers, mental health burdens, and adaptive coping strategies. The study further indicated that mothers experience significant stress due to cultural stigma and limited resources, although faith-based resilience also emerged as an important coping mechanism. The findings call for immediate action in Pakistan, including stigma-awareness campaigns, telehealth services in rural areas, accessible therapies at subsidized rates, workshops to assist mothers in developing coping strategies.*

Keywords: Caregiver Stress, Cultural Stigma, Intellectual Impairment, Lived Experiences

Introduction

There is growing evidence that mothers' well-being is impacted by these responsibilities. Compared to mothers of children who develop normally, mothers usually report poorer health, including more depressive symptoms or greater levels of stress, anxiety, malaise, and sadness (Blacher & Tan Mink, 2004). Additionally, compared to a typical family, children with disabilities are more likely to live in a household that is under stress (Baxter et al., 2000). Due to the additional demands placed on the parents' time, energy, finances, emotions, and perception that their child's needs are not being sufficiently met (Olsen et al., 1999). As a result, moms may be more sensitive to high levels of personal discomfort, which might negatively impact the child's and family's wellbeing (Plant & Sanders, 2007).

The study's goal was to ascertain the coping strategies, stress levels, and mental health issues of parents in Lahore, Pakistan, who had children with intellectual impairments. One hundred parents of children with ID were recruited through outpatient child psychiatry. This study investigated the anxiety and sadness levels of parents of children with intellectual disability (ID) and looked at their coping mechanisms. The average age of the parents was 35, and 70% of them had severe anxiety and depression. The majority of the parents

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(86%) were female. Self-distraction, behavioral disengagement, and venting were the primary coping mechanisms employed by parents to manage their anxiety and despair. (Sheikh et al., 2018). The purpose of another study was to "examine the challenges and issues families in Karachi, Pakistan face in providing informal social support to a family member with an intellectual disability. Parents who give up on their own needs and goals for their kids experience anxiety and a reduction in tolerance. Another major problem is family members' lack of assistance, communication, and support. Depression and suffering can be brought on by stigmatization and discrimination from friends, family, and the school. The study underscores the critical need for continuity and coordination of care and support. Siblings, close friends, and religious beliefs bring consolation and wellness. Parents have an opportunity to show a shared commitment to care if they can connect with similar families (Lakhani et al., 2024).

In one study, Kumari et al. (2024) assessed the psychological stress of parents of children with ID. In total, 170 mothers participated in the study. A total of 14 different reasons were believed to be responsible for the mother's stress. PSS showed a clear linear relationship with the values of four variables. These variables included: a) monthly family income per capita; b) socioeconomic position; c) the participants' occupation; and d) the length of their impairment. The cohort's total mean PSS was 47.14 ± 2.93 . The reference ranges were 45–90 (severe stress) and 19–45 (low stress). The purpose of the study is to qualitatively examine the challenges parents face in providing care and coping strategies for children with intellectual impairments. "Thematic analysis" was used to examine the data. Parents discussed coping mechanisms and the intricate societal, familial, and personal ramifications of having a child with ID. The five themes that emerged were emotional and psychological challenges, financial challenges, social challenges, children's core disorder challenges, and coping strategies. In terms of coping abilities, parents used a variety of strategies to get beyond obstacles, such as self-control, learning and growth, extracurricular activities, therapy, seeking assistance, etc. This research examines the difficulties parents of children with intellectual impairments encounter and the useful coping mechanisms they employ. Additionally, the study provides insightful information that can assist social workers, legislators, and educational institutions in creating efficient support systems for these families (Lu et al., 2025).

Theoretical Framework

According to the Caregiver Stress Process Model (Pearlin et al., 1990), as caregiver stress progresses from primary objective stressors (like the child's behavioral demands) and subjective overload to secondary strains (like marital stress and job stress), it is buffered by coping mechanisms and social support, ultimately impacting maternal depression and well-being. According to McCubbin and Patterson's (1983) Double ABCX Model, A is the stressor (in this example, a child's intellectual handicap), B is the family's resources (in this case, services), and C is the family's viewpoint, which includes an evaluation of the stigma. Pileup demand (aA), improved resources (bB), reevaluation (cC), and either maladaptation or bonadaptation come next. The pressures mentioned in Pearlin's model (such as caring and financial stressors) are a result of the child's intellectual impairment when it comes to the mother's experience of giving birth to a child with an intellectual disability. Qualitative descriptions of psychosocial strain and isolation indicate that this results in a reduced quality of life for the family, higher parental stress, and emotional tiredness. Through the lens of Family Systems Theory, inadequate support (low B/C) is explained in this context. It is demonstrated that this low support increases pile-up (behavioral disorders, for example), reinforcing dysfunctional relationships and identifying the opportunity for resilience intervention.

Rational

In Pakistan, around 1.5 million (2.2%) children have intellectual impairments, and their mothers are responsible for 95% of their care in the absence of any specific governmental assistance structure. This results in generational trauma as siblings are forced to leave school because of the lack of time in their homes, family breakdowns, and as high as 65% maternal depression rates. Other than the few studies conducted in

metropolitan Karachi, no Interpretative Phenomenological Analysis (IPA) study has captured the actual experiences of Pakistani moms. Because 80% of families in rural Punjab, where you are based in Gujranwala, conceal diagnoses due to cultural stigma associated with the label of "failed parents" and an understudied idiographic evidence base of diagnosis shock, economic collapse due to therapy costs, spousal disengagement, and mortality anxiety due to post-parental child desertion, which is used by 97% of caregivers, this IPA study is a national moral imperative. Your study has the potential to prevent family division, create legislation, demonstrate the need for \$0.5 billion in special education funding, and give millions of people a voice.

Objectives

1. To investigate the real-life experiences of Pakistani mothers raising children with intellectual disabilities.
2. To investigate the long-term effects of parenting a child with an intellectual handicap on their social and personal life.
3. To investigate parents' experiences of the root causes of difficulties in managing their child's intellectual difficulties.
4. To investigate the real and psychological problems people may face.
5. To investigate the coping mechanisms mothers use to address their mental health concerns.

Research Questions

1. What are the lived experiences of the Pakistani women raising children with intellectual disabilities?
2. What are the long-term implications for the social and personal lives of a child with intellectual disability?
3. What are the possible impacts of emotional labor on the mental health and overall wellbeing of mothers with a child with an intellectual disability?
4. What are the underlying, invisible factors affecting their experiences as parents of kids with intellectual disabilities?
5. What are the primary coping strategies used by moms to address their psychological problems?

Study Design

To learn more about the lived experiences of women raising children with intellectual impairments, a phenomenological research design (PRD) was employed.

Sampling

The research sample was the mothers of children aged 18-55 years with intellectual disability. The sample size was five, and the sampling technique adopted was non-probability sampling. Participants were recruited from Lahore, Multan, and Gujranwala for data Collection. Purposeful sampling was adopted, which enabled the selection of information-rich cases with the ability to give detailed information about the lived experiences of caregiving mothers of children with intellectual disabilities. The subjects in the study's sample were all female. They were aged between 18 and 55 years. The socioeconomic background of all sample members was within the middle group, so no variation in the socioeconomic background was found.

Inclusion Criteria

The mothers of autistic children who could read and write were involved in this study. They must have firsthand experience with their own child. 18 to 55 is the age range. This study was carried out with mothers only. Participants need to have the cognitive skills needed to understand and respond to the questions. The consent of the participant to participate in the research process must be indicated.

Ethical Considerations

All aspects of the study have been conducted in compliance with the APA Code of Ethics. The participants should be well aware of the objective, method, and potential risks of the study. Informed consent was obtained prior to the interview. Confidentiality and anonymity were respected. They were allowed to withdraw from the research at any time. Deception was only used when it was necessary, and a full debriefing was conducted to explain any deception used during the study. No physical or psychological injury. They will be given the choice to leave.

Measures

Semi-structured interviews were used to collect data. An essential qualitative study technique was semi-structured in-depth interviews with mothers of IDD, ensuring that the interviewing process was uniform while still allowing for the flexibility of capturing individual experiences of the interviewees. This "semi-structured" interviewing allows the opportunity for a comprehensive understanding of participants' thoughts, feelings, and opinions that may not have been uncovered in a fully structured interview. It is one of the best methods for acquiring detailed information, according to Kallio et al. (2016).

Procedure

The authorities must get authorization for data collection before they may access the sample and conduct the study. The protocol question was translated into Urdu to make it more understandable to the participants. Participants were provided with the purpose of the study and requested their consent to participate. Data was collected by interviews. During the interview, the researcher guided the interviewee to ask them related questions in order to explore various aspects of the research. Transcription was done (verbatim writing, which captures the nuances in the participants' responses) after the collection of the data. By developing themes from the coding of the gathered data, thematic analysis was carried out. After the collected data was transcribed from its voice recording format, the IPA technique was employed for theme analysis.

Analysis

IPA is a qualitative approach that looks at how individuals understand their experiences in social and private contexts. Interpretative Phenomenological Analysis (IPA) was primarily developed by psychology professor Jonathan A. Smith of Birkbeck University of London. Smith (1996) is the developer of IPA, a qualitative research method that aims to capture the in-depth, subjective experiences of people, especially in health and clinical psychology, in the 1990s. IPA is particularly helpful when the need arises to comprehend how people experience things and how they interpret their experiences in particular situations. IPA is a technique that was derived from phenomenology, which is a means of comprehending an experience from the participant's point of view, and hermeneutics, which is a method of interpreting the experience's underlying meaning (Irfan et al., 2025). When finishing an IPA, it's also essential to follow a few fundamental processes. First, participants' experiences are thoroughly described through in-depth, semi-structured interviews.

The researcher does a thorough analysis of these transcripts. To familiarize oneself with the facts, one must first read the transcript. The participant narrations should next be analyzed in order to identify themes. To find the general patterns in the participant narratives, these themes will then be grouped into more comprehensive superordinate themes. Every step of the iterative analysis process, which may need several efforts to obtain a profound understanding from the data, requires a twofold hermeneutic approach (Smith & Larkin, 2009). IPA offers insights into how people interpret experiences and occurrences and is especially helpful in the examination of complicated, delicate, and little-studied phenomena. IPA may be used to learn more about how individuals view the world and how it influences their behavior, attitude, and other mental processes (Smith & Larkin, 2009).

Results

The transcriptions of each participant's interview revealed the following superordinate themes, which are related to the individuals' real experiences.

Superordinate Theme	Master Theme	Emergent Theme
Emotional Challenges	Mental Health Challenges	Initially, there was denial, despair, and disbelief at the diagnosis. Persistent worry resulting from a child's reliance and unpredictable behavior Emotional depletion, weariness, and sadness in mothers
	Emotional Resilience	Spiritual coping via faith and prayer (reliance on the Quran) Developing as a mother and finding purpose in life
Social Impact	Social Perception and Stigma	Mothers are called "bad parents" by society. Family blame, rumors, and threats of divorce from spouses
	Family Dynamics	The spouse's practical and emotional absence Anger between siblings and extended alienation from the family.
Financial Issues	Economic Burden	special education and therapy costs in comparison to low income, career sacrifice, and family financial dependence.
	Resource Constrains	The absence of ID-specific services in Pakistan. Transportation barriers to urban treatment facilities
Coping Strategies	Seeking Support	limited access to services provided by NGOs and the government.
	Personal Adaptation	It may be difficult to obtain remote medical treatments.
Awareness and Education	Knowledge Gaps	Creating habits that are organized at home Experience and self-education from medical experts
	Need for information	Desire for workshops on mother training ID awareness efforts that are culturally relevant are necessary.

Interpretation

Numerous superordinate and subordinate themes emerged from the examination of the lived experiences of moms of children with intellectual disability. These involve the emotional struggles and resilience of mothers, social effects, economic pressures, coping mechanisms, and awareness. This indicates the multifaceted nature of caregiving, which is in line with studies conducted in the same field regarding caregivers' burden, stigma, and coping strategies (Lazarus, 1984).

Emotional Challenges and Resilience

Mental Health Challenges

Emotional difficulties were common, especially after diagnosis, when mothers felt shocked, denied the diagnosis at first, and became highly anxious. This is consistent with other studies, which show that parents of kids with ID suffer from greater levels of psychological stress and depression (Olsson & Hwang, 2001).

One of the participants expressed:

"When I was first informed by the doctor about my child's illness, it all just crumbled for me. I was shocked. I still get anxious daily since I depend entirely on my child."

This is characteristic of the caregiver stress syndrome, which is normally caused by persistent caregiving activities and uncertainties (Hayes & Watson, 2013).

Emotional Resilience

Even under stress, the mothers showed resilience, which was largely anchored in spirituality and meaning-making. Religious coping is a well-known protective strategy used in stressful situations in life (Pargament, 2001).

Another Participant Reported:

"I pray and read the Quran; it gives me patience and fortitude."

This is an example of emotion-focused coping, wherein people make use of their inner resources, such as religion, to cope with stress (Lazarus, 1984).

Social Impact

Social Perception and Stigma

Stigma, blame, and negative societal attitudes were also identified by the mothers. This finding aligns with the literature that identifies stigma as one of the key problems faced by families of children with disabilities (Goffman, 2009). A few participants mentioned that:

"They think I am a bad mother, people talk about me, even my own family blames me..."

Family Dynamic

Familial relations were impacted by caregiving pressures, which included inadequate support from the spouse and conflicts between siblings.

This finding is consistent with previous studies indicating that caregiving burdens may interfere with familial relationships (Kersh et al., 2006).

Another participant replied:

"Since my husband does not contribute much to bringing up our child, I am mostly responsible for this task. As a result, I experience feelings of stress and loneliness. Meanwhile, my other children feel ignored since I focus on one particular child."

The results demonstrate that familial dynamics involve role disharmony and emotional distress.

Financial Burden and Resource Constraints

Economic Burden

The financial burden related to caregiving was another major issue, specifically because of expenses for therapy and the inability to earn income. Indeed, according to the literature, families having kids with ID tend to experience economic difficulties (Emerson, 2003).

One participant added:

"Therapy and education expenses are quite high, and we find it hard to cope financially due to the lack of money. I quit my job to look after my kid, and now it has become even harder. Sometimes we have to rely on our family."

This indicates the connection between caregiving and low economic productivity.

Resource Constrains

Participants identified systemic obstacles, such as a lack of resources and accessibility issues. This finding is supported by research conducted in lower and middle-income countries, where disability-related resources are scarce (World Health Organization, 2011).

Another participant shared:

"There are not many facilities that cater to children like mine in this region. Facilities are mostly located in major cities, and it is hard and costly to travel to these cities. Therefore, my child does not receive adequate treatment."

Coping strategies

Finding Support

There is a lack of accessibility to formal support structures in terms of institutional care.

A few participants described:

"I tried accessing the services of the government and NGO's, but it was very hard. When such services were available, it was difficult to access them, so I had to do everything by myself."

According to the study findings, the absence of social support can intensify caregiver stress (Cohen & Wills, 1985).

Adaptive Techniques

The mothers used techniques such as adopting a routine and learning by themselves.

Another participant emphasized:

"Trying to keep up with a routine at home because it calms down my child. I am always learning new ways of doing things from what doctors say and my experience."

These coping strategies fall under the category of problem-focused coping (Lazarus, 1984).

Awareness and Education

Knowledge Shortage

It emerged that cultural beliefs on ID viewed it as a punishment.

One participant replied:

"The people in our society don't know anything about this disorder. Instead, they look upon it as a punishment to the family and discriminate against them, including my child's school."

This highlights the poor mental health literacy (Jorm, 2012).

Training and Awareness Requirement

Training and awareness programs were strongly needed by the participants.

The majority of the participants mentioned:

"There should be proper training workshops conducted for the mothers, wherein we will learn how to properly look after our kids. Also, we require awareness campaigns that will make people understand these kids."

This corresponds to the significance of parental education and community awareness (UNICEF, 2019).

Discussion

The study's conclusions, which are based on the Caregiver Stress Process Model (Pearlin et al., 1990), provide light on the complex situation Pakistani moms of children with intellectual disability (ID) must deal with. This theory states that the initial shock, denial, and pessimism that accompany their child's diagnosis are the primary sources of stress. The cumulative impact of secondary stressors that trigger emotional reactions in women, including mental health conditions, ongoing anxiety, depression, and emotional exhaustion. The emotional distress mentioned above was similar to the research by Neoh et al. (2022) and Scherer et al. (2019), which emphasized the vulnerability of mothers of children with developmental disabilities with regard to depression and exhaustion—both types of psychological distress exacerbated by the stigmatizing effects of the negative family reaction under the general theme of Social Impact.

Sibling hostility and marital emotional/present absence complicate the Double ABC-X Model by McCubbin & Patterson (2014), in which the ID functions as a chronic 'A' stressor that disrupts family stability ('B' components), leading to family crisis ('X'). McConnell et al. (2022) connected these differences with increased caregiver strain, whereas Mirza (2009) noted economic dependency and service unavailability as

a result of their experiences. In addition to the absence of services tailored to individuals with ID and transit limitations in Pakistani cities, economic hardship and resource scarcity are shown to be comparable to structural hurdles in international research. Goals 3 and 4 of the knowledge gap are about feeling punished by God and being rejected by peers and the school system. Regarding the cultural attitudes that cause isolation, Hassall et al. (2005) point out how socially disregarded elements like ignorance worsen the negative effects of emotional labor on wellbeing (research question 3). The emergence of a coping theme has two branches in Pearlin's model of problem-focused coping. The first is the mediated route, which involves getting some government and NGO funding but not being able to use it. The other consists of individual coping strategies and modifications through routine development and self-education. Religious coping provided stress protection, although spiritual resilience via Quranic belief and personal empowerment were positive characteristics of the ABC-X models.

Conclusion

The varied experiences of being a mother of a child with ID in Pakistan are reflected in the outcomes. These realities include psychological pressures such as shock upon diagnosis, worry, and fatigue; stigma and family disruptions; economic stress due to therapy expenses and service unavailability; and a lack of cultural awareness that views ID as a divine punishment. However, mothers have been seen to be quite resilient in coping with these stressors through self-directed learning, family-structured life, and relying on the Quranic faith as a source of coping. This study has emphasized the importance of the interventions needed in Pakistan, including education campaigns in the communities, services provided in urban and rural areas, training programs for mothers, and support groups from living reality to coping strategies of all the research objectives and questions.

Implications and Suggestions

Organize classes on cultural harmony to raise awareness of mental impairment and dispel the notion that God Almighty would exact revenge. To make treatment more accessible and cheap, expand the alternatives for ID treatment in Pakistan's rural areas, especially through teletherapy. Establish mother training on a daily living, coping, and emotional strength basis. Make efforts to build better family relationships and connections through family support for issues related to brothers and sisters, and spouses. Lobby for changes in the financial policies of governments and NGO's to reduce the gap in resources and encourage career continuity for mothers.

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