ORIGINAL ARTICLE

DOI: https://doi.org/10.63050/jpps.21.04.258

JPPS JOURNAL OF PAKISTAN PSYCHIATRIC SOCIETY WWW.JPPS.PK

EXPERIENCES OF MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITIES IN SPECIAL SCHOOL SETTINGS IN KARACHI, PAKISTAN: AN EXPLORATORY QUALITATIVE STUDY

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Submitted: March 20, 2023
Accepted: December 27, 2024

ABSTRACT

OBJECTIVE

To explore the experiences of mothers of children with intellectual disabilities in special school settings, and to understand the beliefs, views, feelings, specific challenges and lived experiences of raising a child with Intellectual Disability (ID).

STUDY DESIGN

Exploratory qualitative study.

PLACE AND DURATION OF STUDY

Four schools for special needs students in Karachi, Pakistan from July 2018 to February 2019 (6 months).

METHOD

Qualitative interviews were conducted with mothers with ages ranging from 18 to 55 years and with only one ID child. A total of 19 mothers agreed and took part in the study. Prior to the start of interviews, written informed consents were taken from all mothers for the interview session, that were conducted in the participants' local language. The results gathered were analysed by using thematic framework analysis method comprising five steps.

RESULTS

Five major themes were identified that reflected the experiences of mothers of children with intellectual disabilities: (1) Diagnosis and Reaction to Diagnosis, (2) Maternal Concerns and Future Uncertainties, (3) Effects on Mothers and Coping Strategies, and (4) Perspectives on Support Systems and Recommendations for Improvement. Each theme provides insight into the unique challenges and resilience of mothers navigating their caregiving roles.

CONCLUSION

The themes identified conclude that mothers' sufferings are caused by the societal attitude and the adequate provision of health, educational, monetary and moral help. This necessitates the establishment of appropriate and efficient measures, resources and assistance for mothers coping with this stigmatising situation.

KEYWORDS

Child; Coping Skills; Intellectual Disability; Pakistan; Resilience, Psychological; Thematic Framework Analysis.

INTRODUCTION

Intellectual disability (ID) is a severely stigmatising condition that requires the use of immense public healthcare resources.[1] People with ID experience health inequalities compared to the general population. In the United States, the standardised mortality ratio for people with severe disabilities was found to be 8.4, while in Australia it is 4.9 for all levels of ID.[2] Intellectually disabled people have greater healthcare requirements than the overall population, and these needs are frequently unrecognised and unfulfilled.[3] It adds to current health inequality, chronic ill health, and premature deaths. There are numerous physiological, psychological, social, and developmental influences that lead to this discrepancy, in addition to life experience.[4]

A meta-analysis of 52 studies found prevalence rate of intellectual disability was 10.37/1000 and the highest rates were seen in countries from low- and middle-income countries. Higher prevalence in low and middle income countries is of concern given the limitations in available resources in such countries to manage intellectual disability.[1] Harris reported the prevalence of ID to vary between 1% and 3%, globally. Among those with ID, mild, moderate, severe, and profound affects about 85%, 10%, 4%, and 2% of the population, respectively.[5] Pakistan has one of the highest documented rates of childhood intellectual disabilities globally, with 65 per 1000 cases for mild ID.[6] Parents especially mother who provide most of the care for their son or daughter, face major trials due to their parental duties, in addition to the insensitivity they face when raising a child with ID.[7]

There is growing evidence that these responsibilities impact on maternal well-being, Mothers tend to have poorer health, for example reporting more depressive symptoms or higher levels of malaise, depression, stress and anxiety than do mothers of normally developing children.[8] It is well recognized that families of children with disabilities are under greater stress than other families.[9] Due to the additional demand on the parents' time, energy, finances, emotions and possible feelings of inadequacy about their competence to deal with their child's needs.[10] Consequently, parents specifically mothers can be at increased risk for excessive levels of personal distress which in turn can adversely affect the wellbeing of the child and the entire family unit.[11]

The overall well-being of informal caregivers, such as parents caring for a disabled child, has been elevated to the level of public concern.[12] Thus, the goals of US governmental efforts such as Healthy People 2010 (U.S. Department of Health and Human Services, 2000) have shifted toward giving assistance to such families. Hence, developing meaningful and successful interventions, services, and supports requires an understanding of parents' experiences, particularly the elements that affect their wellbeing. This is an area of research that deserves further attention.[13] In Pakistan interventions like Learning through play (LTP) significantly promote child health by supporting attuned interaction between mother and child, increasing maternal awareness of the physical and emotional needs of young children, and encouraging nurture and attachment. Therefore, the aimed was to explore mother's experiences, particular challenges and lived experiences of raising a child with ID, and especially the perspective of Pakistani mothers caring for such children.

METHOD

The Ethical approval for the study was taken from Ethics Committee of Karachi Medical and Dental College prior to the implementation of the study. A written approval was also obtained from each institution preceding the data collection.

This was an exploratory study which used qualitative data collection methods to elicit the experiences of mothers of raising children with intellectual disability. We conducted one-to-one, in-depth, semi-structured interviews with the mothers to understand their beliefs, views, and feelings about caring for ID children. This study was conducted in Karachi, Pakistan from July 2018 to February 2019.

The study's target demographic was mothers of intellectually disabled sons and daughters with the children aging up to 19 years and residing in Karachi. The mother's age was also specified and those between 18 to 55 years were selected. Mothers who had only one child with ID, able to understand English/Urdu and give written informed consent were included. Mothers who themselves had any sort of disability, either physical or mental or not willing to participate were not included in the study. There was only one category of mothers in the target population, i.e., those whose children were attending special schools.

Data Collection

The study employed a purposive sampling technique to select participants, who were mothers of children suffering from intellectual disability. A total of four schools for special needs students were approached, namely: Pakistan Centre for Autism, Markaz e Umeed School for Special Children, Karachi Vocational Training Centre and Learning Hands Rehabilitation Centre. All of them granted permission for data collection, following which mothers of ID children were requested to participate in the study. A total of 19 mothers enrolled in the study. All the participants were asked to give written informed consent and were free to withdraw at any time. The assessments were all done by detailed qualitative interview, and there was no invasive procedure.

In-depth qualitative interviews were conducted between November 2018 and January 2019 using a topic guide developed by the research team. This guide was informed by discussions within the team and relevant literature and focused on key areas, including mothers' acceptance of their child's condition, the impact of the condition on their lives, and their suggestions for healthcare services and training for mothers of children with intellectual disabilities. Additional probing questions were asked to capture detailed insights. Demographic information was also collected, including age, occupation, education, social status, and family structure. The topic guide was prepared in both English and Urdu, though for the interviews Urdu language was used as it is the local language of Karachi. Each interview lasted approximately 30 minutes and was recorded with participants' consent. Researchers conducted at least one interview per institution.

Data Management and Analysis

The Interview recordings were transcribed verbatim, initially in Urdu, and subsequently translated for analysis. We employed a combined inductive-deductive approach for thematic analysis, allowing themes to emerge directly from participants' responses while also considering constructs informed by existing literature and the topic guide. Framework analysis was applied to the data following a structured process. The first stage involved familiarization with the data, achieved through repeated reading of transcripts to gain a comprehensive understanding of participants' experiences. Next, initial codes were identified by coding recurring ideas and patterns within participants' responses. These codes were then grouped to create overarching themes, allowing for a clearer organization of concepts. In the reviewing stage, themes were refined to ensure they accurately represented the participants' experiences, followed by defining and naming each theme to create a coherent narrative aligned with the study's objectives.

Finally, the findings were synthesized into a report, addressing the research questions and providing a structured account of the participants' perspectives. Microsoft Excel was utilized to manage and organize data effectively. Excel facilitated the coding process and helped maintain a structured approach to identifying and tracking themes.

RESULTS

This study identified five major themes reflecting the experiences of mothers of children with intellectual disabilities: (1) Diagnosis and Reaction to Diagnosis, (2) Maternal Concerns and Future Uncertainties, (3) Effects on Mothers and Coping Strategies, and (4) Perspectives on Support Systems and 5) Recommendations for Improvement. Each theme provides insight into the unique challenges and resilience of mothers navigating their caregiving roles.

Participants' Characteristics Table 1 illustrates the demographic characteristics of the study participants.

Table 1
Demographic Characteristics of Participants.

	No. of Respondents	Percentage %
20-30 years	1	5
30-40 years	12	63
40-50 years	6	31
Occupation/Employment status		
Private	1	5
Government		
Daily Wages		
Own Business	2	10
Housewife	16	84
Social status		
Middle Class	15	78.9
Upper Class		
Lower Middle Class	4	21
Education		
University	5	26
High School	7	36.8
Middle School	5	26
Primary	2	10
None		
Family structure		
Nuclear	11	57.8
Joint	8	42
Child's primary disability		
Autistic	3	15.7
Slow Learner	11	57.8
ADHD		
Down Syndrome	3	15.7
Others	2	10.5

Diagnosis and Reaction to Diagnosis

Most mothers first noticed signs of intellectual disability in their children around the age of three, typically manifesting as delayed milestones, limited responsiveness, or challenges in adaptive behaviour. Initial diagnoses often confirmed suspicions, though reactions varied widely. Some mothers, already aware of developmental concerns, accepted the diagnosis calmly. Others experienced reactions of shock, disbelief, or self-blame, questioning what could have been done to prevent the condition. One mother expressed her devastation, saying, “Why is she like this? What was the problem which occurred with her? And why me only?” (Interview 010). Others attributed the condition to external factors, such as stress during pregnancy or lack of family support.

Maternal Concerns and Future Uncertainties

A recurring theme was mothers' deep concern for their child's future, particularly in a society where resources and acceptance for children with intellectual disabilities are limited. Worries centred on the child's well-being, social inclusion, and the lack of supportive facilities. As one mother noted, “In countries abroad, special children are treated in special facilities, which show remarkable improvements, but nothing as such is provided in Pakistan” (Interview 007). Despite these challenges, some mothers remained hopeful, placing their trust in religious faith for their child's future. Mothers also expressed frustration with the lack of affordable medical resources, with one mother explaining, “We have paid around 10-20k for a single MRI, which adds up to a huge monthly expense” (Interview 016). Family dynamics, particularly with siblings, added additional stress, as some siblings found it difficult to interact positively with the child with intellectual disabilities.

Effects on Mothers and Coping Strategies

The demands of caregiving had profound effects on mothers' mental, social, and physical well-being. Numerous mothers reported feelings of depression, anger, and regret, often comparing their lives to others and struggling with societal expectations. Socially, they felt isolated, unable to attend events or engage in community activities, as one mother lamented, “There is neither social life nor any other life. We cannot go to any wedding” (Interview 002). Physically, mothers reported exhaustion and neglect of their own health, with some experiencing physical ailments like increased uric acid levels because of stress and lack of rest.

Coping strategies varied among participants. Some mothers sought solace in religion, praying for their child's improvement and attending counselling sessions. Others internalised their struggles, avoiding discussions about their challenges with anyone, as one mother shared, “I don't know what to do; I can't talk to anybody about myself” (Interview 005). A few mothers actively pursued special classes and techniques to communicate better with their children, demonstrating their resilience and commitment to supporting their child's development.

Perspectives on Support Systems and Recommendations for Improvement

Mothers shared their perspectives on societal attitudes and the support systems available. Although some people were understanding and supportive, but most mothers encountered negative reactions, with individuals questioning their parenting or suggesting it was “their fault.” One mother expressed this sentiment, saying, “Wherever you go, people talk about you and ask what you did that your kid became like this” (Interview 003).

To improve the experiences of families with intellectually disabled children, mothers recommended increased governmental support, including the establishment of specialized facilities and training programs for parents. As one mother noted, “There should be workshops for parents too, where we could learn how to tackle and deal with these children” (Interview 010). Other parents advised prioritizing special education for intellectually disabled children, emphasizing that it could help them acquire skills for a more independent future. A mother advocated for special schooling, stating, “Yes, you should get them admitted because if they cannot study, they will at least learn some skills” (Interview 018).

Table 2
Themes and Subthemes in the Experiences of Mothers of Children with Intellectual Disabilities.

Theme	Subtheme	Description
Diagnosis and Reaction to Diagnosis	Initial Signs of Disability	Mothers first noticed signs such as delayed milestones and limited responsiveness, usually around the age of three.
	Reactions to Diagnosis	Mothers' reactions included acceptance, shock, disbelief, and self-blame, with some questioning what could have been done to prevent the condition.
	Attribution to External Factors	Some mothers attributed their child's condition to external factors like stress during pregnancy or lack of family support.
Maternal Concerns and Future Uncertainties	Concerns for Child's Future	Mothers expressed worry about the child's future, well-being, and social inclusion, especially in a society with limited resources for children with disabilities.
	Frustration with Limited Resources	Frustration over lack of affordable medical resources and support facilities; expenses like MRIs posed financial challenges.
	Impact on Family Dynamics	Strain within the family, particularly sibling relationships, where siblings sometimes struggled to interact with the child.
Effects on Mothers and Coping Strategies	Psychological and Emotional Impact	Mothers reported depression, anger, regret, and isolation due to caregiving responsibilities and societal expectations.
	Social Isolation	Limited ability to engage in social events, leading to isolation and loss of social connections.
	Physical Health Challenges	Physical fatigue and health issues, such as increased uric acid levels, due to continuous caregiving demands.
	Coping Mechanisms	Various coping strategies, including reliance on religious faith, counseling, and special classes to communicate better with the child.
Perspectives on Support Systems and Recommendations for Improvement	Societal Attitudes	Mixed societal reactions, with some supportive individuals but others placing blame on mothers, causing additional stress.
	Recommended Support Services	Mothers recommended government initiatives for specialized facilities, training programs, and workshops for parents.
	Advocacy for Special Education	Emphasis on the importance of special education to help children gain skills for independence, with some mothers urging other parents to prioritise this.

Discussion

This study examined the complex experiences of mothers caring for intellectually disabled children in Karachi, Pakistan by focusing on their reactions to diagnosis, ongoing concerns, effects on their well-being, and the coping strategies they employ. The key findings highlighted that most mothers experience a range of emotional responses upon diagnosis, from acceptance to disbelief and self-blame. They voiced deep concerns about their children's future, the lack of supportive resources, and societal attitudes, which often compounded their stress. The caregiving role significantly impacted mothers' mental, social, and physical health, leading to social isolation and physical fatigue. Despite these challenges, mothers showed resilience, employing religious faith, counselling, and proactive communication strategies as coping mechanisms. They also shared recommendations for improving societal support and institutional resources, underscoring the need for accessible special education and parent training programs.

Most of the mothers noticed unusual signs in their children after birth, but diagnosis was made when their children reached the age of three or started going to school. Some of the most common signs and symptoms included delayed milestones, behaviour problem such as explosive tantrums, difficulty remembering things, difficulty with problem solving things or logical things. This result validates earlier research on the experiences of parents of children with intellectual disability in Ghana. According to this study, most of the parents (85%) found their child's diagnosis when they were two years old or more, with only a few parents reporting the condition was noticed some days post-birth. The most common indicators that parents knew that something was amiss or unusual with their child were the recognition of odd physical traits or/and the failure of the children to exhibit typical milestone activities that are anticipated of children of their age, that include: crying, walking or talking.[14]

Some mothers with a prior suspicion reported acceptance. But disbelief, denial, self-blame, sorrow and despair were also frequent findings. Longitudinal studies also revealed mothers' long-term grief.[15] Similarly, Tali Heiman in the research about parents with special needs offspring, mentioned that the most frequent category found was a negative emotional response. Several parents described feeling overwhelmed, stressed or depressed after initially learning about their child's condition.[16] When asked about the reaction to finding out about the child's disability, a mother said that she wept. Thinking of this disability as a test from god was also a finding reported in another research.[17]

Viewing the interview responses, mothers are vastly concerned about their child's wellbeing, behaviour, future, impact on other children. They stressed upon their needs, lack of available resources and puberty changes. Behavioural change came up as one of the significant stressor in mothers who reported about the aggressive and disturbing behaviour while some of them were harmless. In a previous research, mothers brought up socially embarrassing behaviours, whereas others discussed more serious and disruptive behavioural issues (e.g., hitting, breaking things).[18] Mothers consistently expressed their unease about the future of their child, about the quality of life he/she will have after mother's death. In a similar research, participant shared that for a parent of ID child you do not know the future. Some of them were content with the time they spend with all of their children while some mothers were downhearted about the attention division between their ID child and normal and how it is affecting her other children. One participant was afraid that if she had a second child who was normal, she might end up neglecting her child with a disability.[19] Mothers were concerned about the pubertal changes their child is going through. In one study, mothers voiced worry about their children's intellectual incapacity and sexual vulnerability.[20] One of the stressor was the lack of available resources and special needs for ID child. In a recent research, challenges faced by participants regarding accessibility of specialised programs and services for the child with an ID.[21]

Mothers reported various effects on their mental health and physical, social, professional life. Most of the mothers reported depression, grief, regret, worry, and anger. Some even compared their life with others. In a similar research, mothers of children with ID consistently expressed grief and apprehension about the child's future, and the pressure of caring for a child with ID.[22] Mothers in our research reported social effects which were mainly isolation. In a previous research, mothers of children with ID in the sample stated that the challenges their children faced had a stronger social and psychological implications.[23] Mothers also reported that they could not pursue their professional life. Earlier literature reveals that having a child with ID typically hinders with a mother's ability to obtain employment and puts a strain on the financial state.[24]

Mothers founded several coping strategies to deal with the problems they faced during bringing up of their ID child. Major coping strategy which helped most of the mothers was seeking spiritual help like offering prayers and reading Holy Quran. According to one study, the coping mechanisms included having faith in God and spirituality, praying for help, and having hope for the future.[25] This study revealed suggestions of mothers regarding early signs, treatment, handling and education of ID child, training of mothers having ID child and coping strategies. According to some mothers in this study, parents should not ignore early signs present at the time of birth. Mothers also reported that ID child should be properly treated and handled with love and care. Mothers also emphasised on education of children through teaching them manners and etiquettes along with academic studies. Some suggested that proper training should be given to mothers on how to handle an ID Child. Others suggested that the key to cope with such situation is patience: parents should be patient and without patience nothing will happen. These points were not mentioned in previous studies.

Limitations

The study was limited to mothers of children with intellectual disability from schools in Karachi only. Data were restricted to experiences of mothers and did not take into account the experiences of the fathers, caregivers or service providers, like doctors or social workers. Another imperative limitation was that the mothers in this study were mothers of children with many different types of disabilities, thus having variations in their experiences. However themes mentioned in this study were mentioned by almost all mothers regardless of disability. Mothers with only one ID child were included, and the ID child's age was set to be up to 19 years.

Implications

Our research showed the majority of mothers were concerned for their child's future, and it points towards the need for developing more institutes for special children and the organization of social programs. In most of the interviews mothers reported that they felt improvement in their child's behavior due to special school, and also they learnt many new skills which helped them in their daily activities. This shows the influence of good special schools on ID children and even on their mothers. This emphasises the need for developing more special schools in society in order to relieve tensions on parents so they can focus on activities, i.e., occupation, etc., and also special schools increase skills in ID children and behavioral changes.

Furthermore parents reported prevalence of depression due to financial issues, as fees of special schools are unaffordable. So social programs should be developed in order to help poor parents of ID children. So they can avail special schools for their children and can focus on their daily life activities.

CONCLUSION

This study explored the experiences of mothers of children with intellectual disabilities, revealing a range of emotional and social challenges. Mothers commonly reported emotional stress, depression, anger, regret, social isolation, societal blame, self-neglect, marital strain, physical fatigue, and deep concerns for their child's well-being and future. Given the rising prevalence of intellectual disabilities, this study underscores the urgent need for enhanced support services for these mothers, who often shoulder the primary caregiving responsibilities.

Recommendations

The suggested improvements include developing educational training and therapeutic programs for both parents with a special focus on mothers, providing quality specialised education for children with intellectual disabilities, and strengthening family support services through economic assistance. Achieving meaningful collaboration between families and professionals is also essential to address the needs of the child while considering the well-being of other family members in the need for accessible special education and parent training programs.

ACKNOWLEDGMENTS

All praises to Allah Almighty for all His immense kindness and blessings.

CONFLICT OF INTEREST

None to declare

FUNDING

None

DISCLOSURE

This paper was presented at the First Public Health Multidisciplinary Conference of APPNA Institute of Public Health, Jinnah Sindh Medical University, Karachi, Pakistan on April 6, 2019. Available from: https://jsmu.edu.pk/assets/docs/aiphconference2019/Abstract%20Book.pdf?cv=1

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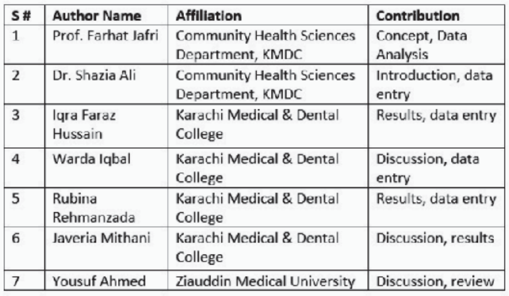
AUTHOR(S) CONTRIBUTION / UNDERTAKING FORM



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