



Exploring Cognitive Abilities: A Qualitative Inquiry into the Experiences of Mothers Raising Children with Intellectual Disabilities

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ABSTRACT

The aim of this study is to explore the experiences and perceptions of parents regarding the development of cognitive abilities in their children with intellectual disability (ID) with a focus on understanding parental perspectives, challenges, and strategies employed in fostering cognitive growth in their children with ID. Understanding how parents perceive the abilities of their children with (ID) in Pakistan is crucial for developing effective diagnostic tool, educational programs and support services tailored to their needs. Given the lifelong limitations associated with ID, gaining insight into parental perspectives can serve as a gateway to implementing targeted interventions that aim to enhance cognitive development and overall well-being in this population. The study employed a qualitative research paradigm, with a purposive sample of 15 participants selected. Data collection involved conducting focus group discussions, and analysis was conducted using Reflexive Thematic Analysis (RTA). The findings highlighted two primary themes: Impaired Cognitive Abilities, specifically focusing on reasoning, problem-solving, and the consequences of these impairments. Mothers expressed concerns about their children with ID demonstrating limited planning, problem-solving, and reasoning abilities in daily life, which significantly affects their integration into society. Consequently, there is a strong emphasis on the necessity to develop an indigenous tool for diagnosing and measuring progress, along with a related curriculum that prioritizes these core skills.



Introduction

DSM-5 TR defines Intellectual disability in significant delays in Intellectual and Adaptive functioning. Intellectual and adaptive deficits begin early in the developmental period. People suffering from ID typically have an IQ below 70. Consequently, they learn slowly, have difficulty with meeting developmental and sociocultural standards for personal independence and social responsibility, and need ongoing support (American Psychological Association, 2022; Shree & Shukla, 2016). Their parents mostly struggle to understand what is happening with their child, what's more how to cope with and help their child. Parents play a crucial role in observing and monitoring their children's behaviors, interactions, and developmental milestones, including language acquisition, problem-solving abilities, reasoning, planning, and attending to environment etc. Through their close involvement, parents can communicate their observations and concerns with healthcare professionals, educators, and specialists, facilitating a comprehensive assessment of their child's cognitive development.

In navigating disabilities, parents often engage their children in a variety of stimulating activities

aimed at fostering cognitive growth, such as shared reading, interactive educational games, puzzle-solving, and exploration of their surroundings. These enriching experiences provided by parents contribute significantly to their child's cognitive development.

Recognizing the pivotal role of parents in shaping their child's cognitive abilities, this study seeks to delve into the experiences and viewpoints of parents raising children with intellectual disabilities (ID). By exploring parental perspectives, challenges encountered, and strategies employed in nurturing cognitive growth in children with ID, the research aims to provide valuable insights and support networks to empower parents in fostering the overall well-being of their children. Moreover, a deeper understanding of the cognitive development of children with ID can inform educators and intervention specialists, enabling them to refine existing approaches and develop innovative tools and interventions tailored to the unique needs of these children. Through collaboration among parents, professionals, and researchers, this collective effort can significantly enhance the holistic well-being and cognitive development of children with ID.

Moreover, ID encompasses significant limitations in intellectual functioning and adaptive behavior, circumscribes and affects individuals across the lifespan. Parents of children with ID face major challenges in their life. Their perceptions related to their mental abilities and expectations for the future of their children with intellectual disability strongly influence the resources they are willing to invest in treatment, training, and education of these children (Owusu et al., 2018). Thus, understanding parental perceptions of Intellectual ability specifically reasoning, Planning and problem-solving ability in intellectually disabled children is crucial for addressing their educational needs during this critical developmental period. Furthermore, this study aims to fill the gap in the literature where there is limited knowledge about parental perceptions about the development of cognitive abilities of their children with ID.

Method

This study was situated in the qualitative paradigm as it seemed best suited on account of the exploratory nature of the study. Moreover, there is limited research on parental perception regarding the cognitive development in their child with ID.

Sample

The sample consisted of 14 mothers of 6-11.11 years old children with intellectual developmental disorder. They were recruited through purposive sampling. The participant's age varied from 25 to 52 years. Those mothers were selected whose minimum education level was intermediate and who had one diagnosed child representing the age and their child was enrolled in special education institution. Moreover it was also made sure to select mothers who earlier has one typical develop child. The participants whose children presented with co-morbidity were excluded. Since the semi-structured interviews were conducted in Urdu, the national language of Pakistan, their proficiency in Urdu was also a prerequisite. The interview guide was designed for the focus group as per the operational definition of intellectual functioning in ID.

Table 1

Demographic Characteristics of the Participants

Participants	Gender	Age	Education	Occupation
P1	Female	29	Intermediate	Housewife
P2	Female	25	Intermediate	Housewife
P3	Female	31	Bachelors	Housewife
P4	Female	43	Intermediate	Housewife
P5	Female	37	Bachelors	Govt. Employee
P6	Female	42	Bachelors	Housewife
P7	Female	46	Masters	Housewife
P8	Female	30	Bachelors	Housewife
P9	Female	38	Intermediate	Housewife
P10	Female	35	Intermediate	Housewife
P11	Female	42	Bachelors	Housewife
P12	Female	26	Intermediate	Housewife
P13	Female	52	Bachelors	Housewife
P14	Female	36	Intermediate	Housewife

Data Collection

Data was collected through focus group discussion. Focus groups are dynamical group discussions used to gather information (Harrell & Bradley, 2009). A predetermined set of open-ended questions was used to guide the focus group discussion.

Procedure

The first author was working as a practicing clinical psychologist at the special education department, Lahore. First and foremost, the project was authorized by the Departmental Doctoral Program Committee of the concerned body. The interview protocol based on the open-ended questions was developed from the definition of the construct from the literature. The participants for the focus group were contacted and a list of parents was made whose children from 6 to 11.11 years of age were enrolled in Special education institutions of Lahore. Later they were contacted and invited to Govt. Shadab Training Institution for Focus Group. The purpose and objective of the present study was explained to the participants. Written consent along with demographic information was taken from them. They were seated comfortably in the room and instructions were given. The focus groups were conducted by the researcher, and she also made sure of the presence of two moderators. The focus group started, and semi structured interviews were conducted where participants were asked about their observations for intellectual ability more specifically reasoning and problem solving of intellectually disabled children. It took a total of 75 minutes. The responses of the participants were audio-recorded, and two audio tapes were used.

Data Analyses and Verification

After focus group, the audio-recorded data was transcribed. Data was analyzed through reflexive thematic analysis (RTA). RTA developed by Braun and Clarke (2006), is an interpretive method firmly situated within a qualitative paradigm. In this approach to analysis, the subjectivity of the researcher is recognized and viewed not as problematic but instead valued as integral to the analysis process (Campbell et al., 2021). The researcher first familiarized herself with the data by manually transcribing the data and reading and rereading the entire data extracts which facilitated a deep immersion into the data. Casual notetaking throughout the analysis facilitated the generation of codes and themes. Transcripts were given serial numbers for identification and participants were also coded serially to ensure confidentiality. Then the shorthand descriptive and interpretive labels for pieces of information i.e., codes relevant to research questions were produced. Some codes were discarded through repeated iterations of coding and further familiarization with the data which were deemed not conducive to interpretation of themes. The researchers made sure to frequently meet and discuss the codes and themes. Then, the coded data was analyzed as to how codes may be combined according to shared meaning so that they form themes and subthemes. After that, the team members reviewed and renamed potential themes, and discarded some candidate themes as they did not serve the research question. Then the researchers finalized the themes and generated a report.

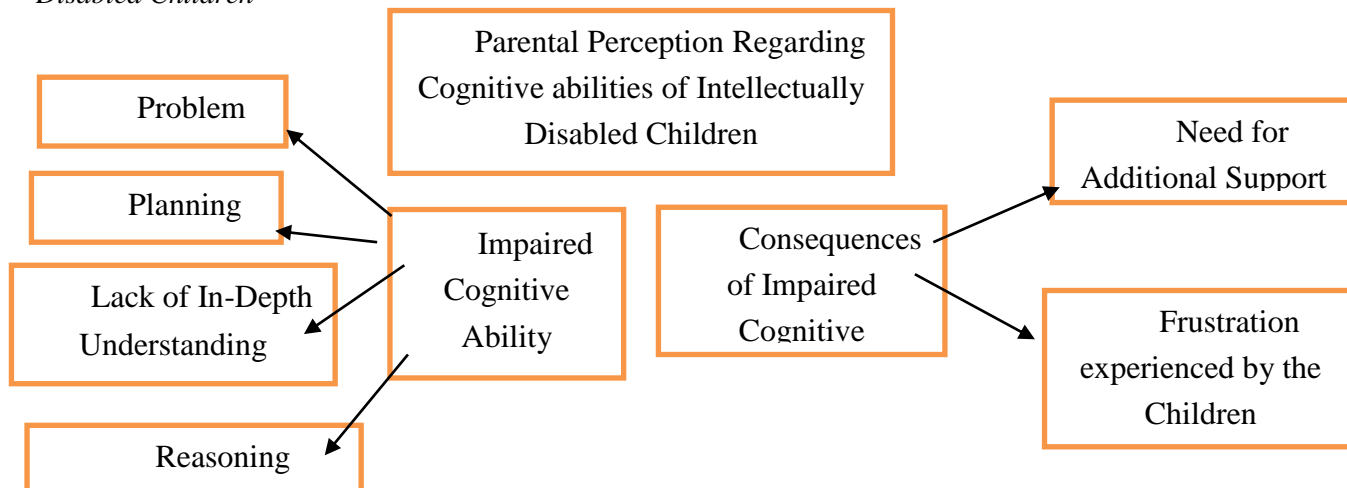
The extracted codes and defined themes and subthemes were shared with clinical psychologists and the given suggestions were incorporated which resulted in a consensus on thematic framework.

Results

The main themes and subthemes related to perception of parents regarding development of cognitive abilities in their intellectually disabled children were generated. The findings unveiled general perception of parents regarding the cognitive abilities of intellectually disabled individuals. The first core theme generated was impaired cognitive ability. The mothers were in view that children with intellectual disability have limited problem solving, reasoning, planning, memory, and lack of in-depth understanding. Moreover, another main theme derived from the transcriptions was the consequences of impaired cognitive ability including subthemes of need for additional support and frustration experienced by the children.

Figure 1

Themes and Subthemes Related to Mothers' Perception Regarding Cognitive abilities of Intellectually Disabled Children



Impaired Cognitive Ability

Impaired cognitive ability was the most reported theme in the interviews. Participants often answered that their intellectually disabled children could not perform mental tasks like their typically developing counterparts. Mothers recognized that children's mental ability differed according to the severity of their intellectual disability i.e., children with mild level of deficit could somewhat communicate their difficulty as means of handling a situation and could learn tasks with lesser difficulty as compared to children with moderate to severe level of deficit.

Problem Solving

All participants collectively reported: "They don't take initiative to solve problems."

P3 reported: "They cannot solve problems using their minds."

P5 reported: "If we tell them two things at a time, they cannot focus on even one of them. meaning that they cannot focus on two of them at the same time."

P9 reported: "Or at home, there will be mother and father, and there is a teacher here [at the school], so they are dependent on them [for handling situations]. That I will do as you tell me. If left alone in a room, they won't be able to get out by themselves."

The participants perceived that intellectually disabled children have poor mental ability to solve problems. They also exhibit hesitancy when it comes to confronting issues directly or taking control of situations necessitating solving problems. They have trouble concentrating on two matters simultaneously, which is the prerequisite of solving problems where multiple aspects of the problem need to be attended. Evidently, they rely on teachers and parents for solving problems and are dependent on their instructions.

Planning

P10, P9 and P12 reported: "They don't use their minds to plan."

P13 reported: "They won't do it verbally nor will they think of another way."

Individuals lack the ability to engage in mental processes to formulate plans. They have trouble coming up with an alternative approach to handle the circumstance. Another participant perceived that the ability to plan varied with the level of intellectual disability, so she reported:

"A mildly intellectually deficient child can somewhat plan, but moderately or severely deficient cannot plan at all."

Therefore, it is concluded that according to the parents, planning ability is not well developed in the children age range from 6 to 11.11 and they are not able to plan a picnic along with the family. Limited speech affects the ability to express and they are not able to plan the events like eid etc.

Reasoning

According to the parents of intellectually disabled individual age 6 to 12 years they are not able to reason about the things that are happening in the surroundings. They are not as aware as the normal child of the same age.

As P1, P5, and P7 mentioned "They are not able to investigate new things, and never felt any intrigue to reach a conclusion.

P3 and P7 stated that, "They do not ask questions rather stay quiet"

Overall parents emphasized that children lack mathematic skills and are unable to learn simple task of adding or subtracting.

Memory

P14 elaborated: "Firstly, they don't remember any incident. Meaning that if they are listening to a story, or doing basic daily tasks, or if they are viewing a drama, they don't talk about it because they don't remember it. Or they will remember one detail but won't remember the whole story."

P7 further added: "Like if they remember, they will tell that there was a boy, he was this, there was a girl. Not more than that."

P5 gave example: "Sometimes, they go too much into details, or if they don't go into details, they forget the main element, or they only remember the main element, or for example, if my student was telling me about his visit to his grandmother's house, he started telling me about the house rather than the incident that occurred. He started with: I will tell you; I went to my grandmother's house during holidays, and what I did, but he started describing the house."

The participants identified that children with intellectual disability have compromised memory which is evident in their way of telling a story. They remember the incident, drama or a story in fragments and have difficulty recalling the sequence in which the event took place. They can only remember a small detail or won't remember at all, so they compensate for it by talking about irrelevant detail as the participant said "he started describing the house" instead of telling the incident that occurred.

Lack of In-depth Understanding

P1 reported: “Miss, they don’t use words like what, why, how.”

P8 further elaborated: “Like a normal child sees something and asks his mother/father what this is, how does this happen, how does this operate, they [children with intellectual disability] don’t have it. If we tell them ourselves, they will know, but they don’t take the initiative themselves, they are not curious about them.”

P2, P4 and P6 added: “They try to understand.”

P9 reported: “Meaning if they are curious about something, all they do is touch.”

The parents recognized that intellectually disabled children lack in curiosity needed for understanding concepts in a comprehensive manner. They also lack the ability to understand matters because of limited mental ability than typically developing children. They identified the difference in their curiosity and level of understanding in a way that typically developing children ask questions and try to process the concepts mentally, but intellectually disabled children try to gain understanding only on concrete level through physical exploration. Therefore, the core skills of cognitive ability are lacking in the children, and they are not able to work independently as children of their age do. Decision making ability is lacking in them.

Consequences of Impaired Cognitive Ability

Parents recognized that children differed in the severity of intellectual deficit and that they needed additional support in their daily living corresponding to their severity level. They also needed task monitoring. Their impaired cognitive ability also resulted in frustration which was expressed nonverbally.

Need for Additional Support

P13 reported: “We have to work more on children with moderate level. If you teach tasks to children with mild intellectual disability, they can incorporate much easily, and they also follow it, but you have to teach children with moderate severity multiple times and have to monitor their tasks.”

The participants identified that severity level of intellectual deficit prompts additional support like giving them repeated instructions and monitoring their tasks.

Frustration experienced by the Children

P 6 reported: “It also happens that they show through their tantrums, [or] these kinds of [problematic] behaviors, that they are facing a problem, [so] they sit down silently, [or] put their head down.”

P 11 further elaborated: “Become irritable.”

P11 added: “Show non-responsive behavior, start hitting other children.”

The participants identified that the children become frustrated when they are facing some problem or are unable to comprehend a situation. Due to which, they are unable to communicate their frustration verbally, which might help them to deal with such situations with the help of others, so they express their stress through tantrums, putting their head down, and hitting others.

Discussion

This study explored perceptions of mothers regarding development of cognitive ability of their intellectually disabled children aged 6-12. The findings unveiled general perception of parents regarding the cognitive abilities of intellectually disabled individuals. The first core theme generated was impaired cognitive ability. The participants were in view that children with intellectual disability have limited problem solving, reasoning, planning, memory, and lack of in-depth understanding. Moreover, another main theme derived from the transcriptions was the consequences of impaired cognitive ability including subthemes of need for additional support and frustration experienced by the children. Mothers of the children acknowledged the limited cognitive abilities of their children. The main theme of impaired cognitive ability in children with ID is supported by Piaget’s theory of cognitive development where he gave the idea that such children have difficulty in attaining skills required in a normative stage of cognitive development (Agheana & Foloștină, 2015). Moreover, the mothers understood that their children faced memory problems which was evident in the details of their stories which aligns with the results from previous research where parents reported poor memory under the umbrella of their academic concerns (Gulzar & Qureshi, 2016).

The findings revealed that mothers recognize that intellectually disabled children need supplementary assistance in their daily life including repeated instructions and teachings and task monitoring. These findings are consistent with findings from previous literature (Ummah et al., 2021). The findings also indicated that children with ID often get frustrated at being unable to comprehend something or completing a basic task i.e., subtheme frustration experienced by the children. These research findings resonated with previous research (Ball & Wolbring, 2014).

Limitations

It is acknowledged that the research study had some limitations. The sample size of 14 parents might

not have been the representative of diverse group of parents with intellectually disabled children. The findings of this study might not be generalizable to the mothers of adolescents with ID. As the data was collected through focus group discussion, there might have been the possibility of socially desirable responses. Future research should focus on perceptions of parents about the cognitive development of intellectually disabled adolescents. It is suggested that the data should be gathered from different provinces of Pakistan to get a better understanding of perceptions of diverse group of parents. Individual interviews are suggested to decrease social desirability.

Implications

The findings of this study can inform clinical psychologists and practitioners of the cognitive challenges children with ID face and guide them about the development of targeted interventions to support their needs. Understanding mothers perceptions can guide the practitioners to develop psychoeducational programs and support services to empower parents in advocating for their children's educational and developmental needs. Furthermore, identification of the limitation in particular area strongly recommends the prioritization of the individual needs of the child. The study highlights the need for policy makers to take initiatives for reduction of stigma around ID and to take considerable measures for promotion of inclusive education and access to specialized education.

Conclusion

This research study highlights mothers perceptions about the development of cognitive ability of children with ID. The findings reveal significant cognitive challenges faced by their children in domains of planning, problem solving, reasoning and memory. Furthermore, the study sheds light on the crucial role of mothers in supporting their children's educational and developmental needs. Addressing the limitations of this study and leveraging its implications can contribute to the enhancement of support services, educational programs, and policies aimed at improving the quality of life for intellectually disabled children and their families.

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