

Perseverance in Search of Support: Insights from Siblings of Individuals with Intellectual Disabilities

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Abstract

Objective: Siblings play crucial roles in each other's lives. Sibling relationships play a central role in children's lives by providing companionship, nurturance, support, and learning opportunities. These relationships are long-lasting within families, especially when one sibling has an Intellectual Disability (ID). The qualitative study focuses on developing deeper insights into siblings' perceptions and descriptions of their relationships with their siblings who have an ID.

Design: The study used an exploratory descriptive-qualitative design. This allowed for an in-depth exploration of the breadth, complexity, and richness of the experiences and challenges faced by siblings living with an individual with an intellectual disability and the generation of extensive contextual information.

The interviews were conducted in the participant's residence.

Methodology: The study's participants were families with children with ID. The families were recruited from one of the special children's schools in Karachi, Pakistan. After institutional ERC approval, the data was collected from the siblings who live with individuals with ID. The individual in-depth interviews using a semi-structured guide were conducted at the participant's home.

Result: The thematic analysis reveals the complex emotional and practical dynamics experienced by siblings of children with intellectual disabilities, including a deep sense of empathy and responsibility and occasional feelings of isolation and frustration. The key themes identified are 1) family dynamics and sibling relationships; 2) siblings' difficulties and disappointments; 3) the significance of familial support and coping mechanisms; and 4) advocacy and Future Planning.

Conclusion: The study concludes that siblings of ID children face diverse emotions and obstacles. They sense empathy and responsibility but also alienation and frustration. Siblings emphasised family support and self-care as essential. Safety and communication issues underline the need for family and societal understanding and assistance. Pakistan's health and social care experts must improve their approach to these families while considering societal perceptions. Use a family-wide strategy to prepare siblings for the demands of their intellectually disabled siblings and societal expectations. Helping siblings manage their relationships with ID family members through informal Social Support is stressed in this study.

Keywords: Siblings' relationship with ID individuals, family support

Introduction

Families as interconnected, interdependent, and responsive units affected by one family member also affect the others (Luijckx et al., 2016). A child with ID affects various facets of family life, including dynamics, roles, responsibilities, and overall family functioning (Tong et al., 2017). Intellectual impairments impede intellectual functioning and adaptive behaviour. Intellectual impairment is characterised by cognitive and adaptive deficits that affect growth and development in all functional areas of life (Schalock et al., 2007; Patel et al., 2020; Patel et al., 2016). Over time, scientific studies have modified the understanding of the influence of social and cultural factors on cognitive functioning and led to a change in the language from mental retardation to intellectual disability or intellectual developmental disorder (Patel et al., 2018). Since most children with ID are typically raised at home by their families, their presence profoundly impacts the well-being of the family members, typically the siblings growing up without ID (Hastings, 2016).

Siblings play crucial roles in each other's lives by providing companionship, nurturance, support, and learning opportunities (Zaidman-Zait et al., 2020). Thus, sibling relationships add complexity and significance when one sibling has an ID. Having a sibling with ID affects other children's social-emotional adjustment and behavioural outcomes (Zaidman-Zait et al., 2020). They may experience feelings of love, empathy, guilt, and resentment, often simultaneously. These emotions may stem from various factors, including caregiving responsibilities, altered family dynamics, and societal perceptions associated with having a sibling with ID (Jacobs & MacMahon, 2017; Kramer-Roy, 2012).

According to Hayden et al. (2019), siblings of children with ID frequently encounter heightened psychological and social difficulties. These challenges stem from various factors, such as the behavioural and emotional adjustment level of the disabled child and the level of parental psychological distress within the family (Hastings, 2016). Research also indicates that siblings of children with disabilities generally exhibit lower levels of well-being as compared to those who do not have disabled siblings; however, this varies across different areas of adjustment (Kovshoff et al., 2017).

Some parents prefer to transfer their caregiving responsibilities to their nondisabled offspring. Such children may experience role reversal; they may indeed take caregiving responsibilities or adopt protective roles towards their brothers and sisters with ID. In a study involving 31 siblings, Bigby et al. (2015) found that siblings played crucial roles in the lives of their brothers and sisters having ID, including monitoring formal care and planning for the future. This role dynamic influenced the sibling bond, fostering closeness and tension.

The experiences and perceptions of siblings of children with ID are multifaceted, encompassing a range of emotions, challenges, and coping mechanisms. Understanding these experiences is crucial, as they can significantly impact the sibling's well-being. This study reports on the early exploratory phase of the primary author's PhD research, which used the Participatory Action Research (PAR) approach to explore the informal support needs of Pakistani families with children with ID. PAR allows people to communicate their thoughts, emotions, and experiences without restraint. In this study, the participants participated in activities and communicated their concerns to the researcher (the primary author) for clarification or to resolve. Furthermore, the participating families worked together to acquire information about informal social support, which could be useful for persons in similar situations. The researcher and participants worked together in the study to design, implement, and evaluate actions to strengthen informal social support.

This paper explores how siblings perceived and described their experiences living with a brother or sister with an ID. Developing a deeper understanding of the perceptions and experiences of siblings can provide valuable insight into their needs, difficulties, and support networks of siblings, facilitating the development of targeted interventions and support services for this population. By presenting the analysis of ID children's siblings in the current study, this paper contributes to the existing literature on ID children's family members' experiences while also indicating the gaps.

Methodology

The flexible exploratory approach of PAR helped the participants to express their experiences, thus providing deep insight into the experiences and perceptions of siblings regarding offering informal social support to a child with ID throughout his or her childhood, recognising the variability of individual experiences (Polit & Beck, 2010).

The research was conducted with the families recruited through a special school in Karachi, Pakistan. The study included siblings of individuals with ID. The age range of the participants was nine to twenty-two years. A total of 13 siblings were interviewed, of which five were females and eight were males. Besides seeking assent of children ($n=7$) below the age of 18 years, consent was obtained from their parents as well. The written consent was sought after verbal agreement, which was obtained from each participant before commencing the individual in-depth interviews.

The head of the school granted permission to inform the families of all enrolled children about the research project. However, participation was entirely voluntary. The families who agreed to participate were contacted by telephone to arrange the meeting date, time, and place. The interviews were conducted at the homes of the families. An initial meeting was held with each family to build rapport and trust. Later, a series of meetings were held, with the entire family actively participating. During the engagement process, the siblings of the identified individual were also involved.

Data was collected using a semi-structured interview guide with open-ended questions that focused on the experiences of living with ID siblings, including challenges and facilitating factors, perceptions about, and recommendations for enhancing informal social support. The guide used was flexible, including new questions emerging during interviews (Grove et al., 2013; Ruslin et al., 2022). The primary author conducted individual interviews to ensure privacy and confidentiality. Each interview lasted 40 to 60 minutes. All the interviews were conducted in Urdu, the national language spoken by all the participants. The audio recordings were transcribed, and field notes were taken to supplement the verbal and nonverbal expressions, enhancing the validity of the data.

The data analysis followed Creswell's (2007) step-by-step approach. The preliminary analysis was initiated simultaneously while the data were being collected. The transcripts and audio files of the interviews were named using pseudonyms for the participants and saved on the computer in a password-protected file. The data analysis began with coding the data, i.e., dividing the text into phrases and assigning labels or codes to each sentence. Using a coding framework, categories and themes were established. The transcripts were re-read each time. After receiving clearance from the institutional ethical committee and obtaining informed consent from participants, the study was conducted within the approved one-year time frame.

The study adhered to the reliability criteria proposed by Lincoln and Guba (1985). Credibility was established in this study by carefully selecting individuals with pertinent experiences and implementing rigorous data-gathering procedures. The researchers meticulously recorded and documented every aspect of the research process, including the methodologies, techniques, and any modifications made during the study, to ensure transparency and the ability to reproduce the results. To

address reliability, the researchers standardised the data collecting instruments, ensured uniform data collection processes, and conducted pilot tests of the tool. The study enhanced its conformability by engaging in researcher reflexivity and critically reflecting on biases, prejudices, assumptions, and preconceptions. The study carefully specified the elements that could affect the generalizability of the findings, including the study setting, participant characteristics, and context-specific factors.

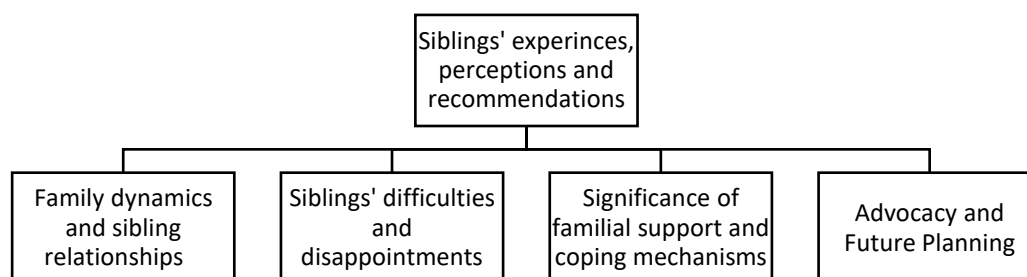


Figure 1-Key Themes

Findings

The thematic analysis has revealed a complex interplay of emotions, responsibilities, and coping mechanisms among the siblings of individuals with ID. While siblings experience a deep sense of empathy and responsibility towards their siblings with ID, they also grapple with feelings of isolation and frustration and the challenges of social integration. Moreover, parental guidance, support from extended family members, and personal coping strategies seem to play pivotal roles in shaping the siblings' perceptions and responses to their sibling's disability. The analysis underscores the importance of holistic familial support and societal understanding in fostering resilience and well-being among siblings of individuals with ID.

The thematic analysis revealed four themes: 1) family dynamics and sibling relationships, discussing distinct familial duties, demanding responsibilities, intricate emotional dynamics, and altered family structures; 2) siblings' difficulties and disappointments, which include societal challenges and concerns, communication barriers, and flexibility about prejudice and inclusiveness; 3) significance of familial support and coping mechanisms, which includes family support and bonding, coping strategies, self-care, and balancing personal and sibling needs; and 4) advocacy and future planning which includes increasing awareness and fostering inclusiveness, collaborative approach to future planning, and formal and informal social support.

Family dynamics and sibling relationships

Siblings feel a strong sense of duty towards their brothers and sisters with ID, recognising their unique role in their families. However, at times, this sense of responsibility is accompanied by sadness. Although siblings have immense affection for their siblings, they may feel overwhelmed by the additional duty and the focus that their siblings require. The sadness, as expressed, may stem from observing their siblings' difficulties, feeling helpless in alleviating their suffering, or being unable to address societal discrimination associated with disability. A sibling stated, "The fact that they need more time and attention makes me sad sometimes. At times, I am ignored" (P:11).

The presence of a sibling with ID within the family unit alters dynamics, leading to increased responsibilities and emotional burdens for siblings. They navigate a complex mix of emotions, including empathy, sadness, and frustration, as they adapt to their sibling's needs. As one of the siblings said, "They are not the same, so I have to be careful. She is not like us, which makes me sad sometimes. I know what she is going through because she is my sister, and I love her" (P:01). Another one voiced, "My parents informed me that my sister is unique, and I feel sorry for her. She cannot perform tasks that I can, so I must assist her" (P:03).

Siblings' Difficulties and Disappointments

Siblings encounter various challenges and concerns when interacting with their ID siblings, particularly when confronted with behavioural issues. In addition to managing disruptive behaviour, some other challenges that may arise include communication difficulties, managing disruptive behaviour, and confronting public attitudes that are harsh and lack compassion toward people with disabilities. The exposure of their ID siblings to unjust treatment, such as instances of abuse or discrimination, can lead to a sense of helplessness and give rise to frustrations. A sibling reported, "I saw one of my cousins making fun of my sister. It was very annoying. I did not like it" (P:08).

The siblings' experiences while navigating relationships with their siblings are reflected in their range of emotions. They demonstrate enormous compassion, love, and flexibility when it comes to satisfying the needs of their siblings, even though, occasionally, they get irritated or upset themselves. A sibling revealed, "I sometimes become upset with my brother. Though he is extraordinarily caring, his behaviour bothers me. He is my brother, and we are family, but his attitude occasionally disturbs me" (P:01). Creating strong, successful relationships with an ID sibling requires adaptability, as the other sibling needs to adjust their actions, speech patterns, and pursuits to match their siblings' strengths, interests, and limitations. A sibling shared, "My

father tells me to have patience with her. Sometimes I do not understand what she wants or says, but I try to be there for her. I am also learning" (P:11).

Significance of familial support and coping mechanisms

To overcome the difficulties the ID children face, siblings highlight the importance of family support and the development of coping skills. Family support systems are critical for providing emotional, practical, and informational support to both individuals with disabilities and their siblings. As one sibling reported, "My grandmother and grandfather play with us. They tell us to ask for help if we need it. I love my grandparents" (P:07). Another sibling added, "When my brother (with ID) is irritated, my grandmother plays with me" (P:05). Prayers, requesting parental assistance, and utilising online resources are reported as the coping mechanisms for dealing with stress and caregiving issues. A sibling verbalised, "Sometimes I look through websites to find out how to deal with the behavioural issues of my sister. It can be helpful sometimes. I want to get more reliable information" (P:10). A sibling added, "My mother asked me to pray to God to heal and bless my sister (with ID) and us" (P:03). Hence, sometimes siblings employ such coping mechanisms to adapt their behaviour to manage their emotions and navigate social situations. One sibling remarked, "I understand why she needs me. I pray for my sister with ID. In the end, God will heal her. Sometimes I cry to see her" (P:08). Despite these challenges, many siblings highlighted that a familial bond, characterised by love and concern for each other's welfare, is ingrained in their family culture.

Siblings also emphasise the need for self-care and maintaining their identity, expressing a desire for personal time and attention, as well as caring responsibilities. Balancing caregiving obligations with personal needs can be tough, but siblings recognise the need to find time for self-reflection, socialising, and hobbies. This need for time for self highlights the significance of setting limits, being clear about what they need from family members, and asking for help when needed. A sibling expressed, "At times, I become impatient and want to take a break. I go out with my friends, but I do not talk much about my brother (with ID) since they do not understand" (P:06).

Moreover, siblings desire personal time and exclusive attention from parents alongside their caregiving responsibilities. They need time to maintain their social connections and a respite from their caregiving duties, highlighting the importance of recognising and paying attention to their needs and emotions. A sibling revealed, "I try to help my mother take care of my brother, but I also want my mother to give me exclusive time" (P:07).

However, parental guidance and explanations about the unique needs of their sibling with ID contribute to siblings' understanding and acceptance. As one of them asserted, "I try to help my mother with household chores because she gives more time to my sibling with ID. I try to contribute to the care as well. I play with him based on his preferences" (P:05). However, disparities in parental attention may lead to feelings of neglect or frustration. A sibling mentioned, "My mother gives more time to my sibling with ID, but then she explains to me why. At times, I get upset" (P:07).

Furthermore, instances of sibling aggression raise safety concerns, prompting the need for safety precautions. Additionally, siblings grapple with communication barriers, experiencing frustration and a longing for reciprocal emotional understanding. One sibling voiced, "My brother sometimes becomes very aggressive; he throws things. I have to hide from him to be safe" (P:01). Another one responded, "Our mum told us to be careful at home, close the door and do not leave your school books on the table" (P:05).

Advocacy and Future Planning

Siblings demonstrate protective instincts, advocate for the well-being of their siblings with ID, and express concerns about their future self-sufficiency. One sibling expressed, "My brother will be unable to study or earn money, which will prevent him from being self-sufficient. I believe we all need to support him" (P:07).

Siblings also genuinely desire to gain a more profound understanding of their siblings' situation and actively contribute to their well-being. One sibling shared, "I wish to know more about my brother's condition and problems. His teacher explains, but it is unclear" (p11). They seek understanding about their sibling's condition and desire answers beyond religious explanations. They actively strive to understand and address the needs of their siblings with disabilities by seeking explanations and information to improve their understanding.

In addition, the siblings express hope regarding improvement in their circumstances, focusing on a better quality of life, increased opportunities for their siblings, and the need for inclusivity. A sibling vented, "We all attend one school, and my sister (with ID) goes to another. There is a special school for her, but sometimes I wish we could go to one school" (P:05).

To sum up, the thematic analysis reveals the complex emotional and practical dynamics experienced by the siblings of individuals with ID, including a deep sense of empathy and responsibility and occasional feelings of isolation and frustration. Moreover, siblings emphasise familial support, coping mechanisms, and self-care practices in managing caregiving responsibilities and personal needs. Challenges such as safety concerns, communication barriers, and societal attitudes towards disabilities are also highlighted, underscoring the need for understanding, advocacy, and inclusivity within family and social contexts.

Discussion

The findings from the overarching themes need to be placed within the existing empirical research and various theoretical perspectives. The results of the current study can contribute to the understanding that ID significantly affects siblings' lives across their lifespans, with varying degrees and types of influences. Also, siblings commonly recognise both positive and

negative aspects of their experiences. Moreover, siblings of individuals with ID face a multitude of unique challenges. Some stem directly from the condition of their sibling with ID, like concerning behaviours and highly demanding healthcare needs (Kramer-Roy, 2012). Others arise due to societal responses or inadequate support systems that overlook the needs and interests of these individuals with disabilities and their families (Davys et al., 2016). The current study findings show that, despite these hardships, most siblings demonstrate resilience and positive adaptation. Another study supports this point that having a sibling with a disability can positively contribute to the typically developed sibling child's psychosocial development through exposure to adversity (Kramer-Roy, 2012; Davys et al., 2016). Moreover, children who assist with their ID siblings' daily care often perceive themselves as having greater responsibility (Kramer-Roy, 2012). They also express greater empathy towards their siblings and are less competitive and unkind, which makes them resilient during disruptions and crises. Their higher resilience is demonstrated when they maintain regular daily activities despite making necessary adaptations due to their sibling with ID (Rossetti et al., 2020). Notably, access to social support networks and successful navigation of support services significantly impact siblings' perceptions of well-being. They are critical factors in helping them maintain their day-to-day activities (Kramer-Roy, 2012). ID is often associated with lower IQ levels, limited social interaction and communication skills, maladaptive behaviours, and additional stress on family dynamics, all of which can influence sibling relationships. However, sibling bond is often considered the strongest within families and is increasingly recognised for its significant role in the psychosocial development of individuals. This role becomes particularly important when one sibling has an ID. Moreover, siblings of ID individuals may face increased caregiving responsibilities and reduced parental attention, depending on the severity of the sibling's ID (Kramer-Roy, 2012; Davys et al., 2016). However, parents can facilitate the development of empathy and understanding among siblings by engaging in open family discussions and interactions during this role maturation period. Moreover, families and schools must communicate, empathise, and collaborate to strengthen this bond between siblings. These activities can promote sibling bonding and resolve differences, leading to a more inclusive and supportive family environment (Davys et al., 2016). Research indicates negative psychosocial impacts, such as pessimism, family distress, and depressive symptoms, among ID siblings (depending on factors like disability type and severity). Feelings of sadness and vulnerability due to aggression, difficulties in acquiring social skills, and decreased pro-social behaviour are also mentioned (Kramer-Roy, 2012; Sommantico et al., 2020). Additionally, managing complex behaviours, difficulty in social situations, and missing out on leisure activities were highlighted as common challenges in this study. Negative emotional responses, such as guilt, anger, sense of loss, and jealousy, were also prevalent among siblings. Congruent with the current study findings, a study reported that some siblings sacrificed their well-being to avoid guilt, and a few sought counselling for mental health needs due to the presence of disabled siblings in their families (Davys et al., 2016). Additionally, studies show that siblings of children with disabilities generally have lower well-being as compared to those without disabled siblings. However, this varies across adjustment areas (Kovshoff et al., 2017). Older siblings of children with ID tend to show slightly higher levels of behavioural and emotional adjustment problems and peer relationships and exhibit higher levels of depression symptoms (Hayden et al., 2019). Likewise, a study reported that siblings expressed frustration and stress associated with caregiving responsibilities and admitted to feeling unprepared for transitioning to this role. They also emphasised the need for adequate information and support to effectively plan their transition into caregiving roles (Rossetti & Hall, 2015). Factors such as gender, age difference, and disability type may influence the quality of these sibling relationships (Rossetti et al., 2020). In the Pakistani context, where families are grappling with various issues, it is the responsibility of professionals working with families of children with disabilities to shift their approach. Instead of solely addressing weaknesses, they should emphasise the strengths of both the family and the child. This can be achieved by integrating interventions rooted in positive psychology, which highlight positive aspects of life with a child with ID, into parental counselling services (Meral et al., 2021). By doing so, professionals can empower parental coping skills, improve psychological well-being, and enhance parenting skills. This could reduce behavioural issues and lighten family burdens, significantly improving overall family well-being.

Conclusion

In conclusion, this analysis shows the complex feelings and challenges experienced by siblings of children with ID. They feel empathy and realise their responsibility but also face isolation and frustration. Family support and self-care are crucial for them. Challenges like safety concerns and communication barriers highlight the need for better understanding and support in both family and society. In Pakistan's context, professionals in the fields of health and social care need to concentrate on improving their practice with these families while considering the overall attitudes of society. To ensure that the siblings are adequately equipped to address the needs of their siblings with intellectual disabilities and to handle societal expectations, it is crucial to use a strategy that is inclusive of the entire family and the siblings. This study emphasises the importance of helping siblings manage their relationships with family members with ID through informal Social Support.

Declaration

Conflict of Interest

None to declare

Funding

No

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