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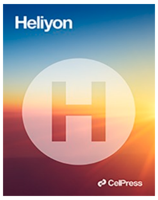

Research article

Informal social support for families with children with an intellectual disability in Karachi, Pakistan: A qualitative exploratory study design

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ABSTRACT

Background: Intellectual disability (ID) is a developmental disorder that causes considerably below-average intellectual performance and adaptive behaviour. In the context of the present study, families raising a child with ID are reported to experience multiple challenges that appear not to be well documented in Pakistan.

Methods and procedures: Pakistan, which was conducted in Karachi, Pakistan, followed participatory action research, in which the researcher and participants examined their existing experiences of informal social support and then created, implemented, and evaluated actions to strengthen this informal social support. A total of five families ($n = 25$) participated in the study. These participating families comprise parents, siblings, and significant others, i.e., aunts, uncles, and grandparents, living with the child with ID. Families with children with ID were selected through a school for children with ID who are under 12 years old. This qualitative action research was conducted in two distinct parts, i.e., a) exploratory part and b) action part. This paper presents the findings of the first exploratory part of the study.

Aim: The exploratory phase aimed to explore and examine the experiences and challenges families may experience with informal social support while caring for a child with an intellectual disability in Karachi, Pakistan.

Findings: Parents often sacrifice their personal needs and aspirations for their children, leading to decreased tolerance and anxiety. Lack of communication, support, and assistance from family members is another significant issue. Stigmatisation and discrimination from school, relatives, and friends can cause depression and distress. The study emphasises the need for a unified and coordinated approach to support and care. Religious beliefs, siblings, and close friends provide comfort and well-being. When parents manage to connect with similar families, they have the opportunity to express a collective commitment to caregiving.

Conclusion: To strengthen the situation, families propose enhancing intimacy and competency within homes and taking action at the governmental level. Governments must provide appropriate services, such as nurses supporting families, support groups, and religious traditions, to promote acceptance and holistic development for intellectually disabled children.

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What this study adds

This paper highlights important new insights into the difficulties Pakistani families of children with intellectual disabilities encounter. It highlights the profound influence of entrenched cultural and religious beliefs on parental attitudes and coping mechanisms, with many families turning to their religious communities for emotional and practical support. The research uncovers disparities in the availability and quality of educational and medical resources, underscoring the urgent need for immediate policy improvements and enhanced community support. It also covers families' substantial financial strain and the crucial role extended family members play in providing care. It offers a thorough examination of the cultural and socioeconomic elements that affect the welfare and informal social support for Pakistani children with intellectual disabilities from an extended family perspective.

1. Background

Intellectual disability (ID) is a developmental disorder that causes considerably below-average intellectual performance and adaptive behaviour [1]. The severity of cognitive impairment, measured by standardised intelligence tests, and social-adaptive functioning determine intellectual disability [2]. Importantly, two people with the same IQ can function differently and need different support. For more holistic care for families with children with ID, social science and public health experts are continually trying to de-medicalise disability [3]. Intellectual disability is a complex mix of physical, psychological, social, and emotional issues [4], impacting the entire family, especially direct caregivers, including parents and siblings [5]. Families with a member with ID have stressful experiences raising a child, are often marginalised, and have trouble accessing resources, including social support [6].

1.1. *Aim of the study*

The aim was to explore the experiences and challenges families may experience regarding informal social support while caring for a child with an intellectual disability in Karachi, Pakistan.

1.1.2. *Family impacts of an intellectually challenged child*

Parenting children with ID can be tough and challenging. Parents face physical care, behavioural challenges, social isolation, mental tiredness, and marital conflicts. They may feel unprepared to care for an intellectually disabled child at first [7]. Informal social support is the help and comfort provided by non-professional sources like family, friends, neighbours, and community members. It includes emotional support, practical assistance, advice, and companionship, usually given voluntarily without formal training [8]. Hence, parents often depend on vital assistance from their immediate family members, such as grandparents, aunts, uncles, and neighbours, to effectively manage their daily routines. This collaborative network not only lightens the load of everyday tasks but also cultivates a sense of communal support and shared responsibility, contributing to the overall harmony and welfare of the family [9]. However, accepting a child with an intellectual disability helps them positively adopt the caregiver position and respond to the child's demands as a family, developing tolerance and adaptability [10]. Social assistance is crucial in aiding these families and their children as they integrate into society. Therefore, informal support services must be designed within families to cater to the specific needs of struggling parents. Ensuring such tailored support can foster an inclusive environment where every family feels valued and empowered to thrive [11].

1.1.3. *Family support for children with ID*

Parenting a child with ID is less stressful and unpleasant for parents with high perceived social support [12]. Life satisfaction is connected to adequate social support for families with children with ID. Social assistance can be formal from professionals or informal from family and friends. Both types of support are needed to help the family manage, adjust, and reduce their concerns and stress [13]. In industrialised countries, formal support is reported more than from friends or informal sources, but there is little formal support in Pakistan. Sheikh, Ashraf [14] found that Pakistani households rely more on spouses, family, and relatives than on formal sources. Families with stronger support systems are more likely to embrace a new child, establish a stronger sense of togetherness, and acquire problem-solving skills that will ultimately benefit the child [15]. Assessing this complex informal social support environment for these families is necessary to understand and help them cope with their challenges. Social well-being is an "interpersonal area that concerns the ability to interact and get along with others, including developing social networks, a sense of belonging to a community, communicating social responsibility, and participating in social and cultural activities" [16]. Findler, Jacoby [17] emphasised that support from immediate family and the community improves family perspectives and future planning for the child with ID; however, a lack of support harms parent-child connection and development [18]. Social support and networks also develop positive interactions and foster empathy and sympathy for other parents in similar situations [13].

As a Low-Middle-Income Country, Pakistan faces development issues such as income disparity, inadequate access to quality education and healthcare, unemployment, agricultural challenges, infrastructure shortages, and political insecurity. In Pakistan, the family is considered a unit with strong and all-weather bonds among the members that provide much-needed support to the family [15]. Similarly, Zuna, Brown [19] state that "regardless of how a family is defined across cultures, they have similar needs, e.g., food, healthcare, social relationships, and care for children." Some cultures broadly recognise the practice of handling issues and concerns collectively and enjoying special moments by sharing happiness [20]. In Pakistan, families raising intellectually disabled children often encounter economic constraints, leading them to depend on informal support networks due to restricted access to formal services. This informal assistance, deeply embedded in cultural norms, is vital for meeting their needs. However, gaps persist in comprehending the utilisation of this support. This study seeks to delve into the dynamics, experiences, and challenges surrounding informal social support within these families to guide the creation of impactful interventions.

2. Method and procedures

This study was the first exploratory phase of a participatory action research (PAR) project. The aim was to explore contextual perspectives and to build and expand upon them in later phases. Publishing the first phase of the exploratory part of this Participatory Action Research (PAR) PhD thesis is crucial. It lays the foundation for the entire study, providing essential context and early insights that inform the subsequent research phases. This phase provides a detailed account of identifying key issues and formulating research questions for the Action Research group, ensuring transparency and rigour in the research process. This first step is a more extensive research endeavour, aiming to produce contextual perspectives, emphasise the significance as an individual investigation, and expand upon these discoveries in later phases. A qualitative exploratory study examined informal social support for families with an intellectual disability in Karachi, Pakistan. The study used semi-structured interviews and purposive sampling to explore the experiences and challenges of seeking informal support [21]. According to Forman, Ghose [22], "an in-depth study of a particular phenomenon involves an intensive and detailed exploration of a relatively small sample, as opposed to an evaluation of targeted concepts from a large sample".

2.1. Setting and participants

The study included parents, siblings, and significant others living with the child with ID. The research was conducted in Karachi, Pakistan. Families with children with ID were selected through a school for children with ID who are under 12 years old. Five families were recruited for the data collection, comprising 25 participants. This group included 8 mothers, 6 fathers, 3 grandparents, 5 siblings, and 3 maternal and paternal aunts. A purposive sampling strategy was used to recruit families who could contribute to generating rich data about the study phenomenon [23]. The qualitative research technique of purposive sampling was meticulously employed to identify families participating in the study. In this case, the selection criteria were specifically designed to gather comprehensive information about the experiences of families with children under 12 who have an ID. In Pakistan, there are a very limited number of schools for children with intellectual disabilities due to resources and funding constraints, and those that do exist tend to be less keen on sharing their time and participating in research studies, which could be due to administrative burden. Hence, engaging families from these schools is challenging. The purposive sampling included a wide range of participants from various economic, social, religious, and ethnic backgrounds. The chosen families satisfied the requirements and consented to participate, offering a comprehensive and diverse viewpoint on the existing informal support services. Despite reaching out to additional families, six families agreed to participate, with one dropping out due to family limitations.

2.2. Data collection method

The interviews focused on the families' understanding of informal social support, their experiences, strategies to identify, gain, and maintain social support, and the influential factors and consequences of using these strategies. A face-to-face, in-depth meeting of 45–60 min was conducted with each family member. Semi-structured interviews permit adequate flexibility for the participants to express their views freely and will facilitate obtaining sufficient information on the desired themes or topics [24]. The interview guide was pilot-tested for its feasibility and appropriateness. A pilot study was conducted to refine the interview guide (IG) and ensure its effectiveness in gathering relevant data. Feedback from the pilot study participants was then used to make necessary adjustments to the IG, such as rephrasing questions or adding prompts, to enhance clarity and comprehensiveness. By conducting a pilot study, the researchers aimed to improve the quality and validity of the data collection process before implementing it in the main study [25]. An interview guide for this qualitative study was created by involving empirical literature for themes, aligning questions with research objectives, and pilot testing for refinement [21]. The interviews were conducted in Urdu, based on the family's choice. All the interviews were audio-recorded with the participant's permission and transcribed simultaneously. The participants were asked to choose the place for the interview, and all the families chose to be interviewed at their residences.

2.3. Data collection process

After the Ethical Review Committee's approval, the researcher met with the school principal and discussed the planning for the data collection. With the permission of the principal of the school, information about the research project was distributed to the schoolchildren by the school administration. Included with the information was a consent form requiring the parent's signature. Potential participants were contacted to inquire about their interest in participating in the study through phone calls and the meeting date and time. Participation was entirely voluntary. Towards the end of the interviews with each family member, mind maps were developed to record the family's concerns and their actual and potential relationships to understand the complexity of the phenomena. The mind maps were shared with individual families to ensure their agreement on the plotted issues. Next, the researcher combined the mind maps of all the families participating in this study and designed one map comprising all the issues and concerns. Furthermore, field notes were also taken to record the nonverbal gestures and expressions of the participants in each phase of gathering the information to contextualise the information shared.

2.4. *Reflexivity*

Using reflexivity and its documentation through reflective journals is an important aspect of qualitative research. Throughout the study, researchers mitigate biases by maintaining reflexivity journals, engaging in peer debriefing, and ensuring methodological rigour. This ensures that findings reflect participants' experiences, not researchers' preconceptions. According to Berger (2015), "reflexivity" refers to engaging in self-appraisal within the research context. Self-reflexivity refers to critically examining one's positionality within the research process and acknowledging its potential impact on various aspects, such as the research setting, the individuals under study, the research questions, the data collection, and the subsequent interpretation of findings. According to Forman et al. (2008), "reflexivity involves being aware of and discussing how the researchers and the research process are influencing data collection and analysis, including the role of previous experience and assumptions made when interpreting the data." This facilitated the researcher in guiding their judgments throughout the process. It enabled them to engage in critical observation, adopt a certain standpoint, and effectively balance participants' perspectives with their chosen inquiry approach. These notes comprise the interpretation of the information shared by the participants throughout the process and the intentional or unintentional influences on the information shared by the participants.

2.5. *Data analysis*

This study followed Creswell, Hanson [26] approach to thematic analysis. The data analysis was initiated after each interaction with the family or families. Since this manuscript is the first phase of the PhD thesis work, every single member of the team took an active part in reviewing the data, which made the findings thorough. The first author carried out the research as part of the PhD studies. The remaining team members formed the PhD supervisory team. The first author did all data collection and initial analysis and then reviewed and discussed as part of the supervision process. We held regular discussions, and each team member contributed their unique experiences and points of view to identify themes, classify data, and formulate findings. Implementing this collaborative technique reduces individual biases and increases the dependability of the findings.

Through collaborative efforts, the research team was able to cross-validate interpretations, allowing them to verify the dependability and accuracy of their findings, which accurately mirrored the participants' experiences [27]. The gathered data was transcribed and translated, and preliminary analysis was done simultaneously. The transcripts and audio files of the interviews were given pseudonyms and saved on the computer with a password. Transcripts were read and re-read iteratively. Data analysis involved thematic analysis, following qualitative research principles. The process included familiarising with the dataset through reading and memoing, considering data saturation throughout, and establishing themes based on recurring patterns and concepts identified in the data using a manual coding process. Codes were derived from the data, reflecting participants' responses and experiences.

2.6. *Study rigor through trustworthiness*

2.6.1. *Credibility*

Refers to the researcher's interpretation and representation of the participant's views [24]. Ensuring credibility in the qualitative participatory action research (PAR) phase involves rigorous engagement with participants, methodological transparency, and reflexivity. The participants were involved from the outset in the study. This collaboration not only validates the relevance of the research but also enhances its accuracy and depth. We rigorously documented the entire research process, including the decisions made and their rationale, to ensure methodological transparency and consistency.

Additionally, I conducted reflexivity, facilitating reflection on the researcher's role and potential biases, thereby reducing subjective influences on the data. We also involved the participants in the data analysis, validating the findings through member checking. We shared the initial findings with them for feedback, ensuring that the outcomes accurately reflected their experiences. I also considered ethical considerations like maintaining confidentiality and obtaining informed consent.

2.6.2. *Dependability*

Dependability was achieved through consistent procedures, including thorough documentation of research processes and methodological decisions [28]. Audit trails, such as detailed data collection and analysis records, were maintained to ensure transparency and accountability. Regular peer debriefing sessions facilitated discussions among researchers to validate interpretations and address any discrepancies, enhancing the reliability and consistency of the findings. Additionally, member checking with participants allowed for validation of interpretations, further strengthening the dependability of the study's results. The constancy of the data and the emerging themes were shared with the participants and the supervisory team to validate the emerging concepts and categories.

2.6.3. *Originality*

The study adopts a comprehensive approach by incorporating diverse perspectives to enhance originality. It involves various family members from different economic, social, and cultural backgrounds, including mothers, fathers, grandparents, siblings, and aunts. This comprehensive method provides a deeper understanding of informal social support systems, revealing how different family roles and histories influence the experience of support. Furthermore, the article demonstrates its methodological rigour through meticulous pilot testing and improvement of research techniques. By resolving any detected flaws during the pilot phase, the study guarantees that the interview guide is skillfully designed to capture the intricacies of informal assistance, thereby enhancing the validity and dependability of the findings.

2.7. Ethical considerations

Before data collection, approval was obtained from the Ethical Review Committee of the concerned department. In addition, permission was sought from the head of the school to access the families for data collection. Each family member was requested to provide consent or assent individually. For children under 18, consent was taken from the parents, and assent was obtained from the children themselves. The informed consent included information on the purpose of the study, the type of information required, the nature of commitment, participant selection, potential risks and benefits, confidentiality, voluntary consent, the right to withdraw, alternatives, and contact information. The participants were assured of confidentiality, using pseudonyms to ensure anonymity. All data and personal information obtained were kept confidential and only reviewed by the investigator. Considering the topic's sensitivity, the questions were asked with due care, and psychological support was provided when they got emotionally disturbed while sharing their experiences of raising a child with an intellectual disability by creating a supportive environment during data collection, offering referrals to counselling support services (when needed), and providing follow-up to check on well-being. This approach aimed to address any emotional needs that may arise and empower families to participate comfortably in the study.

3. Findings

Based on the analysis conducted, three primary themes were identified: the journey of parenting a child with intellectual disability, developing resilience through faith, and social support and fostering informal social support for the families.

3.1. Journey of parenting a child with intellectual disabilities

From the perspectives of parents, siblings, and significant others, the first theme describes the difficulties families encounter on several levels. All the family members acknowledged feeling emotionally strained and bound. Despite being on the same path, the parent has a heavier task and is more stressed. It was found that immediate family members of children with ID forgot their own needs and aspirations and devoted much of their time to caring for the child with ID and setting up facilities and resources. "*As parents, we need to sacrifice our desires for our child so she can get what she deserves*", one of the parents said. Additionally, having a child with ID and the associated obligations makes routine activities more difficult, preventing proper rest, sleep, and comfort. The chance of decreased tolerance and increased hostility increases with physical effort. One of the fathers stated, "*Most of the time, our eating and sleeping schedules are disrupted, and as a result, I get easily irritated and frustrated*"(P.02).

The parents reported sadness and powerlessness when contemplating their child's future. The experience of children's suffering rendered them completely devoid of agency, resulting in persistent anxiety. One parent articulates their experience as depression and hopelessness, characterised by emotional exhaustion and a lack of power or vitality. One of the parents describes it as "*painful to think about the child's suffering, and it emotionally drains you, like having no power or energy*"(P.04).

Caregiving is never easy, but it is even harder when the child has a disability. One of the parents remarked: "*It is a job that never stops; we are constantly occupied and bound*". Lack of respite has consistently been a prevalent characteristic among all individuals, leading to exhaustion. The consensus among all family members was unanimous in acknowledging the high demand for caring for a child with an intellectual disability. One of the grandmothers expressed that her granddaughter, who has ID, requires significant attention.

Consequently, her daughter-in-law is usually occupied with the child, giving insufficient attention to their other children. According to an older sibling, "*At times, mobile phones occupy our younger brother and provide a period of rest or relief*"(P.05). Engaging an ID child in physical exercise or providing them with gadgets might benefit respite.

Participants shared a lack of communication, support, and assistance from formal and informal support groups. Each family faced struggles, but there was a need for enhancement, adopting a more unified and coordinated approach. Many participants experienced emotional pain because of their limited understanding and expertise in childrearing. As a result of this concern, parents express apprehension regarding the adequacy of their efforts to foster their child's growth and development. As one of the mothers said, "*We try to take care of our child, but because we do not understand his needs and requirements, we get confused and overwhelmed*". Another father said, "*I have never seen any such child in our whole family; this is an entirely different and unusual experience for us. We are learning from trial and error and looking for guidance wherever we can get it*" (P.06). The findings revealed that parents require more information about the child's diagnosis, its implications, how to assist their child with daily chores, and how to maintain a strong and stable family.

Besides individual and family concerns, they also shared societal issues they encountered, such as the harsh and degrading statements made about the children by their school, their relatives, and the people surrounding them. In addition, when they meet relatives and friends, they keep their distance from their child with ID. One mother said, "*I got the invitation to attend an engagement ceremony from one of the relatives over the phone, and they mentioned leaving my child (with ID) at home; my whole family felt so bad that none of us attended the gathering*" (P.08). If they choose to attend the ceremony, they are left alone at any get-together or informal social gatherings. An elder sibling shared that "*sometimes it is so embarrassing that in gatherings, people avoid us; we usually sit with our own family*"(P.20). Family members may sometimes experience humiliation, particularly when they find themselves in a public environment. In addition, participants indicated they may experience depression and distress due to cultural ideas, prejudices, and misconceptions, particularly when they engage in negative commentary without considering the emotional toll it may have on them, resulting in familial tension. As a result, individuals often tend to abstain from engaging in prolonged social gatherings and articulate a feeling of detachment from their social network, which encompasses friends and family members. Furthermore, individuals have also experienced victimisation due to having a differently abled family member. One of the siblings stated: "*I feel bad because my brother is not a normal individual … I communicate to my acquaintances that my sibling possesses distinct qualities; nevertheless, they fail to* *comprehend*"(P.15).

They have also been victimised because of the diversity of their family composition, often expressed through feeling pity that their brother or sister is "not normal". Occasionally, they experience embarrassment, particularly in a public setting: "*I share with my friends that my brother or sister is different, but they do not understand*" (P.22). Participants reported that societal beliefs, prejudices, and misconceptions make them depressed and upset when they pass derogatory comments without considering their parents' pain and family stress. Consequently, individuals avoid participating in extensive social events and feel isolated from their social circle, including friends and family members. All the family members unanimously shared that caring for a child with an ID is very demanding. One of the grandmothers shared, "*My grandchild (with ID) requires lots of attention, so my daughter-in-law is busy with her most of the time, and our other children do not get enough attention*" (P.23).

In addition to the social and civic obstacles, the families expressed that the financial burden of caring for an individual with an intellectual disability is significant and reported this issue as having empty pockets to sustain and maintain daily living.

The parents must work to earn money and look after their children. The help of extended family, other children, and friends relieved some of the stress and strain of looking after an ID child, but it still gets difficult. Absence or lateness puts jobs at risk. One of the mothers said, "*I have switched my job to part-time, but still, it becomes difficult to manage. I must leave my children with a maid, but I am unsatisfied. Whenever my child is unwell, I have to take a day off. It is financially challenging. Our earnings are less, and expenses are more. Sometimes, we cannot do enough*" (P.24). To meet the child's needs, the family looks for an economical school and other related facilities required by the child.

3.2. Developing resilience through faith and social support

This theme concerns families' methods for surmounting obstacles and developing resilience.

The study indicated that families with children with ID adhere to religious beliefs, particularly the belief in divine intervention. Individuals are motivated to seek comfort and well-being through their religious beliefs. The individuals anticipated a miraculous event. One of the siblings expressed, "*I pray for my sibling with ID. God will cure him one day*"(P.18).

Additionally, individuals may find serenity and satisfaction by offering their services as volunteers at religious centres. Selflessness and devotion provide a sense of fulfilment and contentment. One of the grandparents said, "*When I pray, I feel more satisfied and have stronger spiritual connections to God. I believe he is observing our circumstances and will help us throughout this challenging period*". An aunt in the family supported this and said, "*We admire our daughter despite her flaws. We have faith that God will protect us and help us through this difficulty. Only God knows the reason for this child's birth into our family*" (P.21).

Families with children with ID require tremendous support from siblings, family, and close friends. Siblings are more compassionate and loving toward their dependents and show high maturity and responsibility. One brother clarified, "*I have to take responsibility; I have to take care of her because she is different; my parents say we are family, and she is part of it; I will take care of her when I grow older.*" (P.19). The research revealed that certain siblings derive enjoyment from assuming responsibility and engaging in household activities due to the support provided by their parents. They were willing to distribute obligations to simplify the dynamics of family life. The involvement in caregiving and household management alongside one's parents was apparent.

The extended family recognises the child's uniqueness and difference and embraces him or her with open arms and hearts: "*We are aware that our child is not typical and is unique. It was initially difficult to accept that our grandchild differs from our other children*" (p.13). It has been demonstrated that the extended family has a huge pool of social support for the family. They stayed there in times of need and crisis; one of the family friends verbalised, "*We cannot do much, but we can just be there or around; I enjoy being with her. I try to encourage and* support *my son and daughter-in-law. I tell them that we should remain hopeful*"(p.14).

The study found that parents tended to establish connections with families undergoing comparable circumstances. Furthermore, they actively steer clear of families that seek to undermine their sense of self-worth and confidence. One of the mothers said, "*We connect with families who face similar challenges while raising a child with ID; try to speak with someone who understands the situation and can offer guidance*". The siblings of children with ID also expressed the idea of re-configuring their friendships. Individuals who teased were typically shunned, contributing to decreased anxiety levels. One of the siblings shared, "*I avoid friends and cousins who dislike my sister; I do not like when they pass mocking comments*"(p.09). The siblings tend to distance themselves from friends who hold negative opinions about their siblings since they find it unpleasant when such individuals make derisive remarks. For siblings, assistance comes from their friends and cousins because they are all eager to assist without any reservations.

All family members expressed a collective commitment to acquiring the necessary caregiving skills to meet the individual needs and expectations of their ID child. Familiarising oneself with the child's growth and development, as well as the educational institutions and associated support systems, assumes significant importance for the family. In addition, discussing with an individual who possesses a comprehensive understanding of the circumstances and can offer guidance on effectively managing the challenging situation, regulating one's emotions, and obtaining pertinent information through social media platforms proved to be of utmost importance. One of the parents expressed that they have been consistently facing challenges in acquiring pertinent information regarding the proper care of their child and determining suitable educational institutions for their child to attend. "*Having acquired this knowledge, we have gained some skills*"(p.18).

3.3. Fostering informal social support for families

Families with children with ID have proposed two levels of recommended measures. The first level focuses on enhancing intimacy and competency within homes, while the second level pertains to actions to be taken at the governmental level.

At the familial level, enhancing social support necessitates investing more time in familial interactions, fostering shared responsibilities, and strengthening bonds among family members. *A mother said, "In the past, we spent time together as a family, but after having this child with ID, there is a need to devote more time and share the concerns we have as a child and jointly address them to receive more* support"(p.16).

In the context of familial dynamics, it is commonly observed that when a child with special needs is present, it becomes imperative to consider each family member's unique abilities and constraints. Subsequently, it is essential to strategically harness or manage these attributes to optimise their impact on the child's overall growth and development. Extended family members residing in the same household, such as grandparents, play a significant role. A grandfather stated, "*There are so many members in our family, and we all have various strengths and weaknesses, but we should* support *one another so that our child can benefit and we can move forward positively. As grandparents, we care for our ID child, and it feels wonderful to contribute*"(p.17). Encouraging their active participation in providing care and involving them in important decision-making processes can foster collaborative contributions and yield favourable outcomes.

In the study, all participants agreed that more support from the government was needed. The primary aspect found to be commonly shared among the participants was the provision of educational institutions, speech therapy, physiotherapy, occupational therapy, basic health check-ups, and behavioural therapy at a reduced cost. A father shared, "*Our child requires speech and physiotherapy. This service is provided by one of the private institutes. These therapies are so expensive that we cannot afford to use them regularly. We pay for transportation and services, which are becoming increasingly difficult to pay for*" (p.10).

Additionally, it was stated that these services should be efficiently integrated into a single-window system, hence eliminating the need for individuals to explore multiple portals. Professionals should organise awareness activities to educate caregivers and family members on the appropriate practices and considerations for raising a child with intellectual disabilities. Caregivers must have access to helpline services staffed by specialists, enabling them to seek assistance when needed. This approach is preferable to seeking support from untrained individuals who may lack understanding of the caregiver's specific situation and contextual factors. An aunt said, "*We wish to get some helpful information from trained personnel to contribute to our child's growth*"(p.07). The active involvement of social media platforms is crucial in promoting knowledge about the societal issues associated with raising a child and promoting acceptance throughout society. Lastly, a significant aspect emphasised by parents is the necessity of specialised early childhood development (ECD) programs for these children to enhance their growth and development. Typically, the cognitive developmental delay of a child may not become evident until they reach school age or beyond. A family may have concerns regarding the possibility of intellectual disability if a child's motor skills, language abilities, and self-help skills progress significantly slower than their siblings. "*My child is nine years old, and I wish I had been able to get him training and education when he was younger*," a mother said. "*I have read that early instruction is crucial to a child's development*". (p.02).

4. Discussion

Having presented the findings from this study carried out in the Pakistani context, the following section discusses how these findings compare with the literature. Parents require a significant period to adapt to the presence of a child with ID [29]. However, once successfully adapting to this new reality, parents are more skilled in providing the necessary support to facilitate their child's development into a responsible adult and a valuable contributor to society [30]. Adopting this perspective makes reducing anxiety easy and enables one's offspring to experience life to its maximum potential [31,32].

One of the primary findings of this study, the first significant one, highlighted that parent experienced an adjustment phase when confronted with the reality of having a child with intellectual disabilities (ID). This aligns with research conducted in numerous settings, as exemplified by families with ID reconciling themselves with their child's condition as a manifestation of divine providence and offering compassionate care [30]. In this study, the interviews with mothers facilitated a shift in perspective for the individuals involved, enabling them to perceive the positive aspects associated with the experience of parenting a child with ID. Furthermore, these interviews fostered a deeper comprehension of the profound influence that the child had on the dynamics and well-being of the family unit. It is anticipated that the families will mutually assist one another in exchanging their experiences about positive and negative emotions while endeavouring to enhance their capabilities and surmount their limitations [33].

In the Asian cultural context, the family unit holds significant importance as the fundamental building block of society and serves as the primary focal point in an individual's existence. The majority of the family structure in Pakistan is typically cohesive, with a strong emphasis on interdependence and the appreciation of familial bonds [34]. Family members actively contribute aid and encouragement to one another, often maintaining this commitment throughout their lifetimes. The familial unit exhibits a compassionate and affectionate bond, wherein members provide assistance and solace to one another during hardship or affliction [35]. Similarly, research claims that the family is central to Pakistani culture, serving as the fundamental pillar around which various aspects of society are constructed. In Pakistan, it is observed that families commonly tend to maintain cohesiveness and remain close to one another throughout their lifetimes [36].

Consequently, family members are strongly dedicated to providing mutual assistance and support over an extended period. Individuals within a family exhibit a collective sense of responsibility, providing emotional support, solace, and assistance to one another due to the deep ties they maintain [37,38]. In the Pakistani context, parents perceive their offspring as invaluable blessings bestowed upon them by God [38]. Consequently, societal norms and values emphasise the utmost importance of meeting the duties and commitments associated with parenthood [39]. In contemporary society, parents exhibit a strong commitment to ensuring the overall well-being of their children, encompassing their physical health, educational development, and comprehensive care [39]. Once a child has been accepted as a member of a family, the family starts advocating for the child's rights and standing within the broader societal framework, regardless of the challenges encountered by society at large in embracing the child [39,40].

Various religious traditions impart significant teachings concerning children and families, irrespective of their particular beliefs. Engaging in these religious rituals has been shown to have a calming effect on individuals, potentially reducing feelings of anxiety [41]. These teachings encompass the following principles: demonstrating love and providing affection towards children; recognising the child as a divine bestowal; emphasising the responsibility of parents and families in nurturing and safeguarding their children; fostering robust familial connections; and promoting the collective well-being of all family members [42]. The considerable impact of belief may have contributed to the family's acceptance of intellectually disabled children and their active support in facilitating their holistic development despite cognitive impairments. This familial bond exhibits self-collaboration, mutual coordination, affection, and compassion [43]. This partnership is devoid of greed, oppression, or negative emotions. It lacks the presence of arrogance, negligence, or detachment, as well as any form of oppression, whether physical or emotional [44]. Few parents said they preferred to handle their children's special needs independently [45,46]. Hence, Parents of children with intellectual disabilities benefit greatly from informal support in helping them learn social and occupational skills, receive vocational guidance, and get assistance with self-care and daily activities [37].

5. Implications

This data was collected during the initial exploratory phase of the action research study and served as the foundation for subsequent phases. However, a few initial insights from this initial phase were as follows:

In a civilised society, individuals with intellectual disabilities are entitled to live their lives with dignity and be treated with respect. Pakistan is a country that has also signed onto the Standard Rules for the Equalization of Opportunities for Persons with Disabilities [47]. This goal can be attained by implementing interventions to foster positive transformations in social awareness, attitudes, and beliefs about this condition. Governments must ensure appropriate services to address children with ID effectively. The government's establishment of academic and vocational training facilities, as well as residential accommodations, should alleviate concerns among parents who hold persistent anxiety over the future care of their intellectually disabled children if the parents outlive them.

Preserving one's health, connections, and socialisation is of essential importance for families as well. Nurses can provide critical support to parents with intellectual disabilities (ID), but their involvement with these families varies across Pakistan. Nurses, Social workers, and other health care providers play a crucial role in supporting families to maintain their regular routines and social connections, mitigating any potential feelings of guilt or embarrassment that may arise. Furthermore, the responsibility of caregiving must not be solely placed on the mother. It is crucial for other family members to actively participate in the care of a child with intellectual disabilities. This collaborative approach may enhance the likelihood of effectively addressing the challenges associated with such conditions.

Ongoing therapy is an essential component of providing support for parents. Professional assistance not only facilitates parental acquisition of the necessary parenting skills for effectively raising children with ID but also aids in their ability to manage the various challenges and emotional strain encountered in their daily lives. An effective parent-professional partnership is a tremendous asset in supporting parental coping. Effective parental counselling, knowledge provision, and expert support have substantially impacted the well-being and relationships between children and their families [48].

The variation in how social support is perceived in Pakistan is influenced by socioeconomic challenges, cultural stigmas, and the limited availability of formal support systems. Under these conditions, informal social support often becomes the primary source of assistance for families with an intellectual disability despite its inconsistencies. This context accounts for the differing perceptions of support

In addition to receiving assistance from specialists, parents can also benefit from participating in support groups. These groups provide a platform for parents to express their emotions and gain insights from one another's experiences and accumulated knowledge. This intervention facilitates individuals' ability to manage their daily responsibilities, mitigates the negative impact of social stigma, and strengthens their adaptive capacities.

Registry of the child along with the family/resource directory at the provincial and federal level by the social welfare department of the ministry to design, plan, and implement interventions for these families, release authentic, up-to-date information for the families, promote provincial parent association and organisation to reach out to the families who are struggling, and organise an annual event at the provincial level for these children and their families based on different supportive activities.

6. Conclusion

This study emphasises the difficulties associated with informal social assistance families in Pakistan encounter when caring for children with intellectual disabilities (ID). These problems encompass emotional strain, sacrifices, and disruptions to their daily routines. Notwithstanding these challenges, individuals exhibit notable resilience and adaptive strategies, deriving strength from their religious convictions, seeking assistance from their extensive family and social circles, and actively acquiring knowledge to enhance their parental abilities. The research also emphasises the societal stigmatisation and prejudice experienced by these families, advocating for heightened awareness and empathy.

CRediT authorship contribution statement

Arusa Lakhani: Writing – review & editing, Writing – original draft, Validation, Methodology, Investigation, Data curation, Conceptualization. **Tazeen Saeed Ali:** Writing – review & editing, Supervision. **Debbie Kramer-Roy:** Writing – review & editing,

Formal analysis. **Dilshad Ashraf:** Visualization, Supervision, Methodology, Formal analysis, Conceptualization.

Data and code availability statement

Data will be made available on request.

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The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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