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Original Article

Exploring the Lived Experiences of Mothers of Children with Intellectual Disability: A Phenomenological Approach

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Abstract

Introduction: Living with an intellectually disabled child in the family is associated with some concerns and challenges. However, mothers who play the traditional role of "caregiver" have to take on more responsibilities for their intellectually disabled children. Thus, they face more pressures and psychological problems and experiences. To this end, this study aimed to explore the lived experiences of mothers of children with intellectual disabilities.

Methods: This qualitative study was conducted using a phenomenological approach. The participants were 12 mothers of children with intellectual disabilities who were selected using purposive sampling. The data were collected through in-depth interviews with the participants. The interviews were recorded, transcribed, and analyzed using Colaizzi's method of data analysis.

Results: Analysis of the experiences of the mothers of children with intellectual disabilities revealed 7 main themes (blame, concerns about the future, child behavioral problems, disrupted interactions, stigma and social isolation, negative thoughts and feelings, and positive achievements) and 16 subthemes that were coded into subcategories of the main themes.

Conclusion: The findings of this study can provide valuable insights into the severity of problems faced by mothers with intellectually disabled children and contribute to adopting supportive treatment strategies for these mothers and improving their mental health. These data can make professionals working with intellectually disabled children familiar with the main challenges and concerns and pave the way for psychologists and psychiatrists to design effective interventions based on the experiences of mothers and the cultural norms of the Iranian community.

Keywords: Mothers, Children with intellectual disability, Lived experiences, Phenomenology, Qualitative research

Introduction

Intellectual disability is a disorder that begins during a person's development and involves adaptive and intellectual dysfunction in the practical, social, and conceptual domains. Intellectual disabilities in people are diagnosed via three criteria: 1) The absence of intellectual functions such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experiences that have been confirmed in clinical and individual evaluations and standard intelligence tests; 2) Impairments in adaptive functioning that lead to the child not achieving developmental and socio-cultural standards required for individual independence and social responsibility; and 3) The onset of these intellectual and adaptive problems in the developmental period (1). Thus, intellectual disability is known as one of the most complex, difficult, and major issues and problems in children and adolescents in human societies which persists into adulthood (2). People with this problem constitute a heterogeneous group with significant variations in prevalence, severity, and type of cognitive and functional impairments, sensory-motor disabilities, and socio-familial problems. These people are of special importance in terms of their effects on the family and society (3).

A huge bulk of studies in the literature indicate that parents of children with intellectual disabilities suffer from more anxiety, depression, worry, and psychological problems than parents with normal children and other children with special needs (4-11). Miller and Chan also showed that mothers of children with intellectual disabilities experience more stress than mothers with naturally growing children and are different from mothers of normal children in terms of personality traits (12). These issues may arise from maladaptation and antisocial behaviors, self-harm, stereotyped actions, cognitive disorders, behavioral problems, nutritional problems, poor adaptive functioning, language deficits, problems in attending public places due to the child's specific conditions, and high costs of treatment and educational services (13). Although the presence of an intellectually disabled child adversely affects all family members and their functioning (14), mothers, due to their traditional role of "caregiver", take on more responsibilities for their intellectually disabled child. As a result, they face more psychological distress and problems (15). According to Witter, the most serious issues and problems faced by parents with intellectually disabled children are:

1. The problem of accepting the child's disability
2. The fatigue caused by nursing and caring for the child
3. The issues related to leisure and free time
4. The financial problems faced by the family
5. The medical, training, and rehabilitation issues (16)

Extensive research has been conducted in Iran on children with intellectual disabilities. For instance, Mohammadkhan-Kermanshahi et al. examined the experiences of mothers having mentally-retarded children and concluded that these mothers devote their lives to their children due to taking too much responsibility. As a result, they endure a lot of problems such as stress, disappointment, and concerns about their future and that of the child (17). Mousavy Khatat et al. examined cognitive, psychological, and social characteristics of parents with more than one exceptional child compared to mothers of normal children and found that the health of mothers with children with special needs is lower in terms of physical and social domains, anxiety, and depression compared to mothers of normal children (18). Furthermore, Narimani et al. showed that mothers of exceptional children have lower mental health than mothers of normal children. They also reported that mothers of intellectually disabled children have lower mental health compared with mothers of blind and deaf children (19). A review of the literature showed that a huge bulk of studies in Iran and abroad have addressed problems and challenges faced by mothers with intellectually disabled children. However, most of these studies have adopted a quantitative approach to exploring these problems. Despite numerous advantages of quantitative methods, they fail to deeply explore various aspects of the phenomenon in question using first-hand experiences of members of the target group (20). Phenomenology is the study of lived experiences and focuses on the world as lived by an individual, not the world or reality that is separate from humans (21). Thus, this study sought to explore and understand the true experiences of mothers of children with intellectual disabilities. To this end, this study employed a phenomenological approach to explore lived experiences of mothers of children with intellectual disabilities. The findings of this study can contribute to understanding the experiences of this group of mothers in the cultural context of Iran. Moreover, the insights provided through this study can be used by professionals working with children with special needs to develop more effective interventions to address the challenges faced by these children and their families.

Methods

The present study was conducted using a phenomenological qualitative method. Phenomenology is a research approach by which the researcher seeks to discover the underlying structure or essence of individuals' living experiences of a phenomenon and finds the integrated meaning that reveals the essence of the phenomenon. Phenomenology does not involve itself in finding rules and principles but instead seeks to perform descriptive analysis that leads to an in-depth and interpretive understanding of social phenomena (21). The participants in this study were selected using convenience sampling from among mothers of primary school children with intellectual disabilities in Yazd Province. Intellectual disabilities in the children were diagnosed by specialists of the Yazd Department of Exceptional Education. The data in this study were collected through in-depth interviews with the participants because the main source of information in phenomenological studies is the deep and in-depth conversations between the researcher and the participants (22). Thus, the interviewer tries to reach the real world and lived experiences of the participants, without trying to lead the conversations in a specific direction. Before conducting the interviews in this study, the participants were assured that their statements, information, and identities would remain confidential. Besides, the interviews were conducted in full compliance with all ethical standards. Since qualitative research focuses more on information obtained about a situation or event than the sample size, the data in this study were saturated after in-depth interviews with 12 individuals. The participants were mothers with at least one intellectually disabled child. In total, the participants had 7 sons and 5 daughters with intellectual disabilities. The questions asked during the interviews focused on mothers' experiences of living with people with intellectual disabilities (to reveal the participants' experiences, thoughts, feelings, concerns, worries, and motives). The next questions were asked depending on the responses provided by the participants. The researchers recorded the interviews and listened to the participants' statements carefully to determine if the content of the interview was understandable or whether there was a need for follow-up questions or what other points should be asked in the interview. Afterward, the interviews were transcribed, and the resulting data were coded and analyzed. After classifying the codes and merging the related codes, the formulated themes and subthemes were placed into specific thematic categories and subcategories. Finally, all the extracted themes were classified according to the objectives of the study.

The rigor of the qualitative data was established using four criteria of credibility, dependability, confirmability, and transferability. In this study, the researchers tried to carefully avoid any kind of bias in the data collection process. The researchers also referred to the participants several times to ensure the credibility of the content of the interviews after categorizing the content. Besides, to validate the data, after conducting the interview, extracting the data, and coding them, the participants reviewed the data and the findings to confirm their compatibility with the researchers' interpretations of the content. Thus, possible ambiguities and inconsistencies were resolved through member checking. Finally, the collected data were analyzed using Colaizzi's method.

Results

As pointed out earlier, upon the completion of the interviews, their content was transcribed. Then, the significant statements related to the mothers' experiences of living with intellectually disabled children were extracted. A total of 257 themes were extracted from the participants' statements. The extracted themes were categorized into 7 main themes and further subcategorized into 16 subthemes.

The main themes (and the related subthemes) identified in this study were: blame (self-blame, spouse blame, and public blame), concerns about the future (concerns about the fate of the child after the mother's death, concerns about the child's puberty and adulthood, and concerns about the child's social life), child behavioral problems (conflicts with parents and conflicts with siblings), disrupted interactions (disrupted interactions with the husband and disrupted interactions with the child), stigma and social isolation (isolation due to negative thoughts and isolation due to public behaviors and reactions), negative thoughts and feelings (negative thoughts and negative feelings) and positive achievements (personal achievements and family achievements). Table 1 lists the main themes and subthemes identified in this study and presents examples of the participants' statements.

Table 1. The main themes and subthemes identified in this study

Examples of the participants' statements	Subthemes	Main themes
I know I should blame myself. I should have taken a genetic test before getting pregnant (Participant 2). I must have done something wrong that this terrible thing happened to me (Participant 6). Sometimes I hate myself (Participant 9). If I was a good person this wouldn't happen to me (Participant 8). I'm being punished for my sins (Participant 10).	Self-blame	Blame
My husband blames me for everything (Participant 3). My husband says that if I knew how to raise a kid, he would not be like this (Participant 4). My husband always brags about his sister's kids and blames me for our child's behavior (Participant 6). My husband tells me I've made him miserable (Participant 7). He tells me it's my fault I did not take care of the kid (Participant 9).	Spouse blame	
Once an old woman on the bus told me that I have committed a sin and I'm being punished for it (Participant 3). Someone told me God wanted me to be like this because I didn't wear hijab (Participant 7). I wanted to enroll my kid in a sports training course but they told me mentally retarded children wouldn't be welcome there (Participant 11). The doctor told me as I had a cousin marriage I have to pay for it for the rest of my life (Participant 9).	Public blame	
How many years I'm going to live to care for my child (Participant 1). I'm always concerned about her future. I don't know who would support her after my death (Participant 7). I do not like my child to say that I didn't do anything to support him after my death (Participant 6). I don't know how she is going to be raised by other people after my death (Participant 10).	Concerns about the fate of the child after the mother's death	Concerns about the future
I always wonder what will happen to her in the future. She cannot handle her life alone (Participant 1). What will happen to her job and life when she grows up (Participant 2) I'm afraid he will get nervous and aggressive when he grows up (Participant 4). What if he can't get married (Participant 4). How does he want to have children (Participant 12) My child's future is unknown (Participant 8). I get disappointed when I think of his future (Participant 11).	Concerns about the child's puberty and adulthood	
I don't know if he can manage his life when he starts an independent life (Participant 5). I fear he will turn into an incompetent/inefficient person in the future (Participant 6). She cannot handle her personal affairs (Participant 7). I fear she will be abused (Participant 9).	Concerns about the child's social life	
She is always fighting with me (Participant 1). She is very stubborn (Participant 2). He hits himself (Participant 4). When he gets mad, he beats himself (Participant 8).	Conflicts with parents	Child behavioral problems
She fights with her brother every day (Participant 7). He scrabbles his sister's face (Participant 12). She refuses to go anywhere with her brother (Participant 9).	Conflicts with siblings	
Her father does not take any responsibility (Participant 1). I don't care if he goes to a school for exceptional children, but his father does not accept it at all (Participant 4). His father does not like him and does not treat him warmly (Participant 5). My husband does not help me take care of the child (Participant 12). My husband does not allow me to take him to the doctor (Participant 6).	Disrupted interactions with the husband	Disrupted interactions
Sometimes I hit her hard, but I regret it soon and caress her (Participant 1). I'm fed up with the way she behaves. She annoys me (Participant 2). I do not know what to do to make him take care of his personal affairs (Participant 4). I have to give in (Participant 5). I have to threaten him every day (Participant 12). I get angry quickly and get upset (Participant 8). I'm screaming and yelling at him so he stops misbehaving (Participant 11).	Disrupted interactions with the child	
I think people laugh at me with this kid so I will not go out with him anymore (Participant 3). When we go out and compare my child with other children, I get very sad, so I decided not to go out (Participant 9). I'm always thinking about what others may say about my child (Participant 2). If I say my child has a mental problem, they think he is crazy (Participant 12).	Isolation due to negative thoughts	Stigma and social isolation
Other kids bit her and make fun of her. I don't allow her to go out. I also don't go to parties (Participant 1). We do not visit our relatives anymore (Participant 4). We have not told our relatives anything yet, we will hide our child's problem (Participant 11). People around me feel pity for me. I do not like it (Participant 10). Going to public places adversely affects our mood. The way people look at us is agonizing (Participant 6). People ask many questions about my child's problem. They want also to know if I had taken him to a doctor and I do not like thousands of repetitive questions. It's not up to them. I hate other people's interrogative behavior (Participant 12).	Isolation due to public behaviors and reactions	
I think I cannot have a good life with this child anymore (Participant 4). I always think about my misfortunes and miseries (Participant 7). I know no one can help me I have to grin and bear it (Participant 9). God is not going to help me anymore (Participant 11). I think a lot about death and grief (Participant 3).	Negative thoughts	Negative thoughts and feelings
Sometimes I feel great sadness that will suffocate me one day (Participant 12). I feel despair (Participant 4). The feeling of guilt never leaves me alone (Participant 8). I feel I'm inferior and miserable (Participant 9). A serious problem I cannot get along with (Participant 7). There is no single night I go to sleep without crying (Participant 11).	Negative feelings	
I have a very good relationship with God. I feel He loves me so much that He has given me this child, and He will reward me for all my sufferings in the hereafter (Participant 2). She is very emotional. She always tells me that she loves me, and this raises my self-confidence (Participant 1). Sometimes he makes us happy and gives us a lot of energy (Participant 5). God has given me strange patience and endurance (Participant 6). My child is extremely loving and kind (Participant 8).	Personal achievements	Positive achievements
Ever since we found out the child has a problem, my husband has been very considerate of me and we argue less frequently (Participant 8). We believe in God more and support each other more frequently (Participant 5). Our relatives are very supportive. They often visit us. Everybody loves the child (Participant 12).	Family achievements	

Discussion

This study explored the lived experiences of mothers of children with intellectual disabilities. Analysis of the data from the interviews revealed 7 main themes and 16 subthemes as discussed below:

The participants stated that they were concerned about the future of their intellectually disabled children. The main concern for most of the mothers was who would take responsibility for the child in the future after the mother's death. Many mothers perceived a tragic future for their children after the mother's death. They believed that their children would be left alone and no one would take care of them. Furthermore, the mothers expressed serious concerns about the time their children would decide to marry and start a marital life. They were worried about the children's marital relations, their jobs, and their social life. They also stated that they were disappointed and helpless about the child's future. In line with these findings, Mohammadkhan-Kermanshahi et al. examined the experiences of mothers of children with disabilities and pointed out that the mothers were worried about their child's future and demanded help and support from the government and educational centers (17). Saif-Naraghy and Nadery also concluded that parents of disabled children expressed many worries about the future of their children. The parents could not reasonably pay attention to the current situation of the children and their needs (23). Thus, mothers of children with intellectual disabilities are concerned about the child's future due to the child's dependence on the parents because they do not know who will take care of their children in their absence or at old age. As a result, informing mothers about government and non-government services and support and making efforts to use all available insurance and service delivery capacities for children with disabilities can promote mothers' peace of mind. On the other hand, these intense worries come to the surface partly due to the mother's negative thoughts and perceptions, leading to their frustration and helplessness. Thus, counseling and psychological services can be useful in helping mothers to accept their thoughts and feelings. These mothers need to be encouraged to show commitment to their values. They should be also empowered to take care of their children. It should be noted that educating mothers can alleviate many of their worries about their children's marriage and their future. Helping mothers come up with a realistic picture of the future of children with intellectual disabilities is very useful. Moreover, educational and support facilities and structures must be directed at empowering children with intellectual disabilities to prepare them to start their social life and implement training programs for these children in special schools to enhance their life skills. Perhaps the greatest concern of this group of mothers is how to attend to the public domain and build an independent life for their children. Thus, related organizations or institutions can provide the required educational and support facilities for these children.

The participants in this study reported many instances of blame that disrupted the normal course of their life. The instances of blame reported by the participants were self-blame, spouse blame, and public blame, which reduced the mothers' functions in various educational and training domains. A mother who is always exposed to reprehensible thoughts and feelings and loses her efficiency and ability to care for and support her child due to cognitive integration with these thoughts needs training in recognizing thoughts and feelings. Hence, she can build a happier life for herself. Furthermore, the criticisms directed by the husband against the mother will disturb the mother and decline her performance. Many fathers who are unaware of how the intellectual disability is developed in the child, blame and humiliate mothers for this problem. Moreover, negative public views and people's unreasonable attitudes due to unawareness of intellectual disability also worsen this problem. In addition, some people, willingly or unwillingly, blame mothers for their children's behaviors. Thus, mothers need to be empowered to cope with these problems. Furthermore, some measures must be taken to raise public awareness about children with intellectual disabilities. Damrosch and Perry pointed to self-blame in mothers with intellectually disabled children and their problems in adapting to and coping with this disability (24). In addition, Mohammadkhan-Kermanshahi et al. and Dini Turki et al. reported that parents of intellectually disabled children suffer from feelings of loneliness, anxiety, worry, boredom, helplessness, self-blame, emotional exhaustion, chronic grief, and concerns about the child's life in the future (25,17).

The participants in this study also complained about the behavioral problems of their intellectually disabled children. Some mothers reported that they suffered from severe helplessness and psychological distress caused by these behavioral problems. They did not know how to deal with these problems. These behavioral problems could be attributed to the incompatibility of the child with the parents and the siblings. This incompatibility was due to the physical presence of the intellectually disabled child in the family and the possible problems caused by the misbehavior and emotional-behavioral problems of the child. Some aggressive behaviors can affect the psychological and structural order of the family and decline the mothers' ability to perform her daily functions. Numerous studies have demonstrated the effects of behavioral problems of intellectually disabled children on mothers. For instance, Crnic et al. reported that children with intellectual disabilities are at higher risk for behavioral problems than normal children. Behavioral problems observed in these children have troubled all teachers and educators. These problems are considered a great obstacle to educating these children. Thus, their teachers and even parents are always trying to find a solution to remove this great educational obstacle (26). Moreover, teaching parenting techniques to parents of these children as well as teaching life skills to an intellectually disabled child can be very helpful. One of the most neglected domains of education is teaching behavioral control skills to mothers of children with intellectual disabilities.

The participants in this study reported negative thoughts and feelings experienced by them that were very common and sometimes very intense. These thoughts and feelings included anger, rage, frustration, guilt, and shame that developed in the mother due to the problems related to the intellectually disabled child. Thus, the mother is more likely to show negative reactions such as aggression, verbal humiliation, and cursing followed by feelings of helplessness, guilt, and shame when dealing with the child. In a similar vein, Baker et al. showed that mothers of children with disabilities tend to experience stress and mental crises, and the presence of children with disabilities threatens the adaptation and physical and mental health of mothers and exposes them to the risk of depression, anxiety as well as negative thoughts and feelings (13). The mothers who are unaware of relaxation and mindfulness techniques cannot accept their thoughts and feelings. Thus, they fail to enrich their lives and are stuck in their mental traps. Accordingly, they are more likely to engage in some behaviors that worsen their negative thoughts and feelings, and they will have many difficulties when dealing with their mental problems and those of their intellectually disabled children. As a result, they will experience failure, and this recurrent chain of failure will fill them with feelings of hopelessness and despair. Accordingly, there is a great need for extensive training programs for mothers to help them learn how to improve their children's mental health. Hence, one of the most urgent needs of mothers of intellectually disabled children is to provide instructions to enable them to accept and recognize the feelings and emotions caused by problems related to intellectually disabled children.

Another problem reported by many participants in this study was related to social stigmas, a socio-psychological process that begins with labeling and leads to social exclusion and isolation (27). A majority of the mothers stated that they had to give up many of their social activities and ties and retreated to isolation to escape from this social stigma related to their intellectually disabled children. They were ashamed of having an intellectually disabled child and were afraid their child would be ridiculed and mocked by others for the child's misbehaviors and preferred to stay at home. The data from the interviews indicated that this isolation could occur for two reasons. The first one was the very negative thoughts of the mother herself, which have led to isolation due to cognitive integration. The second reason was public reactions and perceptions leading to resentment of the mothers and their isolation. Many researchers (e.g. Friedrich et al.) stated that some parents of children with disabilities are socially isolated (28). Gupta and Singhal also reported that having a disabled child not only affects the parents but also influences their relationships with relatives (29). Thus, to reduce parental isolation and social stigmas, it is necessary to educate mothers to recognize their thoughts and raise public awareness about how to deal with children with disabilities and their parents.

The participants in this study pointed to many problems that occurred in their lives due to their disrupted interactions with their husbands well as the child. These interactions were disrupted due to the pressures and stress experienced by the mothers as well as the father and sometimes led to the mother's indifference toward the husband and the child. The participants also reported that their husbands did not take any responsibility for the child. Besides, this lack of responsibility even disrupted their marital relationships, leading to feelings of despair and loneliness in the mothers. Similarly, Brobst et al. reported that parents of children with disabilities experience high levels of marital stress and dissatisfaction (30). Furthermore, Risdal and Singer highlighted the negative effects of the presence of an intellectually disabled child on parental interactions and stated the probability of divorce in these parents was 3 to 6% higher than in parents with normal children (31). In addition, due to mothers' unawareness of social skills and parent-child interactions, the mother's interactions with the disabled child were also disrupted, causing the child to not cooperate with the mother and follow her instructions and resulting in a kind of mutual stubbornness. Providing instructions to mothers and addressing parent-child problems can improve parent-child interactions.

Despite many hardships and bitter experiences, some mothers of children with intellectual disabilities reported that they had a happy life due to their positive achievements. They praised their positive feelings about their disabled children and considered them a divine gift and a source of joy and effort in the family. Some of the mothers reported that the presence of an intellectually disabled child in their lives has made family members have closer interactions and help each other. Some participants also stated that having an intellectually disabled child has led them to grow spiritually and morally, accept differences, and have more patience in life. Accordingly, Scorgie and Sobsey stated that the existence of a disabled child leads to a new experience and sense of humanity in normal children by helping their disabled sibling and promotes the personal and spiritual development of family members (32). Highlighting these positive experiences in families with intellectually disabled children and helping other mothers to change their attitudes toward these children can be very helpful. Many parents and siblings of children with intellectual disabilities are so involved in the problems, stress, and concerns about the future life of an intellectually disabled family member that they fail to notice such positive and hopeful characteristics. Paying attention to such issues in everyday life and introducing people who have positive and satisfying attitudes even of these conditions can help increase hopefulness in these mothers, change their attitudes, and induce joy and happiness in the families of people with intellectual disabilities. Many individuals and families cannot understand many of the positive personality traits acquired due to the presence of a disabled sibling in the family and thus they are trapped in grief and regret. An awareness of these positive experiences can be helpful for family counseling and guidance professionals and families of children with disabilities or special needs.

One of the limitations of this study was the lack of qualitative studies in Iran on the experiences of mothers of children with intellectual disabilities. Thus, the researchers could not compare the results of the present study with the findings of similar studies conducted in Iran. A few quantitative studies conducted in Iran have focused only on some quantitative variables. Moreover, the participants in this study were dissatisfied with educational institutions and centers and were not willing to cooperate in this research project.

Conclusion

Overall, the findings of this study indicated mothers of children with intellectual disabilities are involved in many pressures, worries, and sometimes a sense of happiness in various psychological, social, and family domains of their lives. Many of these worries and frustrations occur due to unawareness of how to interact with and train intellectually disabled children and get along with their thoughts and feelings, personality traits and attitudes of the mother, problems and maladaptive behaviors of the disabled child, and lack of social support and public education services. Besides, the public culture plays a vital role in the attitudes and feelings of mothers with intellectually disabled children. The perceptions, attitudes, and feedback of people in the community, family members, and even exceptional education officials can also be very effective in the experiences of people living with a disabled person. As a result, it is essential to recognize the mental state of mothers and pay attention to their needs and problems. They also need support from professionals. Moreover, understanding the world of mothers of children with intellectual disabilities and providing support and educational resources for them can improve their mental health. Furthermore, exploring more problems, needs, and abilities of mothers of children with intellectual disabilities can contribute to taking effective measures to solve their problems.

Following the findings of the present study, researchers working in the field of exceptional children are recommended to use qualitative research to explore the lived experiences of people living with children with exceptional needs. Researchers can also examine the lived experience of fathers of disabled children or examine differences in the experiences of living with intellectually disabled male and female children. Furthermore, researchers can employ other qualitative research methods such as grounded theory and case studies to discover and explore the experiences of siblings of intellectually disabled children, their parents, and even teachers and professionals working with these children.

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Conflict of Interest

The authors did not have any conflict of interest.

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