



Research Paper

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Couple Challenges of Families with Adolescent Children with Mental Disabilities: A Phenomenological Study

Fahime Bahonar¹, Mahya Saniee Manesh^{2*}, Mahnaz Kahrizesh³

1. Faculty of Psychology and Educational Sciences, Isfahan University, Isfahan, Iran
2. Faculty of Psychology and Educational Sciences, Kharazmi University, Alborz, Iran
3. Faculty of Psychology and Educational Sciences, Isfahan University, Isfahan, Iran

Article Info.	Abstract
Received: 24.01.2023 Accepted: 16.06.2023	Abstract Parents with disabled children are at the forefront of caring for their children. This research was conducted to analyze the challenges of couples with a teenage child with intellectual disabilities. In the current research, a qualitative method of interpretive phenomenology was used. The population included couples with adolescent children with intellectual disabilities in Tehran in 2021. The participants were selected through the purposive sampling method; 15 couples underwent semi-structured interviews until data saturation emerged. To analyze the data, the Colaizzi Method was used. The result of data analysis led to the identification of 27 initial codes, five axial codes, and two selective codes. The first selective theme, intra-family process challenges, was identified with the sub-theme of the couple's behavior towards each other, the couple's behavior towards the intellectual child, and the children's behaviors with each other. The second selective theme was extra-family process challenges including social and economic problems. In general, it can be concluded that having a mentally intellectual child affects the functioning of the family, especially couples. Considering the importance of investigating marital challenges in different physical, mental, social, and spiritual dimensions and their other effects on the lives of parents of teenagers with disabilities, the findings of this research can be used to develop and strengthen counseling and support services for couples with disabled children.
Keywords: <i>couples,</i> <i>challenges,</i> <i>teenage children,</i> <i>intellectual disabilities</i>	
*Corresponding author Email: Std_mahyasane@khu.ac.ir	

Introduction

Individuals with intellectual disabilities are impaired to understand new or complex information and to apply new skills in their daily life (Pipan, 2012). In general, these individuals experience significant problems in their life; they are at a higher risk of physical diseases and death compared to individuals who do not have a disability (Bourke et al., 2017). As a result, children and adolescents with mental disabilities need the support and care of their families, parents and specialists to continue their lives (Nijs & Maes, 2014; Jansen et al., 2018). Therefore, parents with disabled children would face different experiences in life compared to their peers; this issue can have negative or positive effects (Chan et al., 2022; Whiting et al., 2019; Whiting, 2019). Literature review shows that having a child with intellectual disability undoubtedly affects the functioning of the family, especially couples, because they are considered the main caregivers. Thus, couples would face many social, economic, parenting, marital and personal challenges in wide dimensions. On the other hand, the family faces unique challenges during the adolescent phase of a child with a disability (Correa et al., 2022; Kerr et al., 2022). Hence, the couples' situation may change more. Accordingly, a deeper investigation of the situation of these families, especially the couples' relationship, is important at this stage of the development of children with mental disabilities. The current research study filled the gaps in this area; it provided a background to increase the mental health of the families with disabled adolescents and the adolescents themselves. Therefore, the researchers tried to examine what couple challenges the families with an adolescent with an intellectual disability experience.

Methodology

The objective of this study was to examine the experiences of couples who have an adolescent child with mental disabilities. Therefore, it is a qualitative study, specifically interpretive phenomenological research. The population consisted of couples with an adolescent child with mental disabilities in Tehran in 2021. The samples were selected through purposive sampling method (non-probability sampling method). All of the participants had the experience of an adolescent child with mental disabilities. In order to minimize the heterogeneity of the participants, the inclusion criteria were considered. They were willingness of both parents to participate in the study, residence in Tehran, no reported history of physical and chronic mental illness in couples, experience of having an adolescent child (in the age range of 15-18 years old) who suffers from a mental disability. The participants were selected until the researchers reached meaning saturation. Finally, 15 couples were selected. It should be noted that saturation is the stage in which no more new data emerges in relation to the category; the category has a suitable scope and the relationships between the categories are established and confirmed (Burns & Grove, 2018). Ultimately, all themes were analyzed; they were given to two experts with PhD degree and family therapists to prevent the subjective biases of the researchers. In this research study, in order to collect data, a semi-structured interview conducted by the researchers was used; the main focus of the interview questions was to examine the experiences of couples with an adolescent child with mental disabilities. In order to analyze the data, Collaizi method, which is one of the most widely used methods of analysis in phenomenological research, was used (Mohammadpour, 2012). Furthermore, in order to check the validity and accuracy of research data, the four criteria (i.e., credibility, transferability, dependability and confirmability) suggested by Guba and Lincoln (1994) were used.

Results

The sample of the present study included 15 couples with an adolescent child with mental disabilities. The mean age of the adolescents was 14.53 years, the mean age of the mothers was 43.8 years, and the mean age of the fathers was 46.06 years. 40% (6 individuals) were girls, and 60% (9 individuals) were boys. Considering the education

level, diploma degree (7 mothers and 6 fathers) gained the highest frequency. In addition, the mean of the number of children was 2.06, and the mean of the duration of marriage was 18.93 years.

Table 1. Initial, axial and selective codes along with the participants' quotations

Quotations	Initial codes	Axial codes	Selective codes
After the birth of my disabled child, I became indifferent to my life and my spouse (2).	Marital heartbreak		
Our first two children were healthy, but the third one, who was disabled, made us change all home rules and our lifestyle (5).	Changing the family structure with the birth of a disabled child		
First of all, we were not ready to accept that our child was disabled because both of us were healthy. It was hard to believe it (2).	Denying the child's disability		
Our time is spent taking care of our disabled child in such a way that we don't have time to spend with each other or even to look at the mirror (7).	Not having sufficient time to spend with each other		
I feel that I have become very sensitive. As soon as my wife says something, I react (8).	Irritability		
I am not saying that there are no conflicts in people's lives. However, after we found out that our child was disabled, our conflicts increased (9).	marital conflicts	Couple's functioning considering each other	
My wife and I even filed for official divorce. But we sympathized for our child, and we lived together. However, we no longer have an emotional relationship with each other. We only live in one house (10).	Emotional divorce		
It is true that our child is disabled, but it is very important for me to raise and train him properly. I am always asking my spouse to train him together, but my spouse continues his own way (3).	Not consulting your spouse in training the child		Intra-familial process challenges
I was waiting for my son to fulfill all my wishes, but it didn't happen (4).	Changing parents' hopes and expectations for their children		
Since I found out that my child was disabled, I have thought of him my whole life (7).	Too much attention to the child		
Not always, but there was a time when I only paid attention to my two healthy children and had nothing to do with my third child who was disabled. I wanted to forget him even for a few minutes (15).	Failure to consider the children	Couple's functioning considering the disabled child	
During the struggles, my wife and I quitted for the sake of our son; we have thought of him during our conflicts (9).	Triangulation		
Since I spend more time with him, I continue my own way; I have nothing to do with my spouse considering raising and training children (1).	Failure to pay attention to the role of the spouse in training the child		
We often forget that our child is disabled and has some limitations. We selfishly ask him to fulfill our requests (11).	Imposing demands on adolescents		

Quotations	Initial codes	Axial codes	Selective codes
I don't accept my wife's training method; I think it's wrong because she doesn't behave in accordance with the child's age and disability (12).	Misunderstanding the spouses' training method		
Although I ask my wife to control herself in front of our children, especially our daughter, she struggles in front of her. This makes our children more stressed (14).	The occurrence of parental disputes in the presence of the child		
We are very worried about his life, work, and education (13).	Worrying about the future of the child		
We have two children; one is healthy and the other is disabled. It's true that they don't understand much, but I understand that my disabled son is jealous of my daughter's health (9).	Jealousy of the healthy child		
Since my disabled child has problems, I cannot tell him how to communicate with other children (15)	Failure to communicate properly with the healthy child	Children's functioning considering each other	
Since the other two children are healthy, this one compares himself with them (5).	Comparison with the healthy child		
Not only is there a struggle between my wife and me, but there is also a struggle between my children (11).	Conflicts between the children		
After our family and friends found out that our child was disabled, they started backbiting (6).	Social labels		
Instead of being understood, I experienced rejection from many people, especially relevant organizations (7).	Lack of acceptance and empathy of society	Social problems	
Everyone was asking me about what we did, and what we ate so that our child became disabled. They ask if it was a hereditary problem, and how we have coped with it (12).	People's annoying questions		Extra-familial process challenges
The cost of treatment is really high and taking care of him is so difficult (13).	The pressure of medical expenses		
As a father, I can't afford house rent, treatment, and other expenses (5).	Financial pressures of the head of the family	Economic problems	
From the beginning, I have built my life alone, and now I have no support to ask for money (3).	Lack of financial support		

As it is evident in Table 1, the results of data analysis led to the identification of 27 initial codes, five axial codes and two selective codes. The challenges of the intra-familial process were identified with the sub-themes of couple's functioning considering each other, couple's functioning considering disabled children, and children's functioning considering each other. In fact, the participants admitted that the birth of a disabled child led to a change in the family structure and affected the relationships within the family. On the one hand, the couples spent less time for each other and had experienced indifference in their marital relations; on the other hand, they had to manage their relationships with the disabled child and had to consider his age and disability. Moreover, extra-familial process challenges such as social and economic problems caused couples to be in trouble.

Conclusion

The objective of this study was to examine the challenges of couples with an adolescent child with mental disabilities. The result of data analysis led to the identification of 27 initial codes, five axial codes and two selective codes. The first main theme was intra-familial process challenges with the sub-theme of couple's functioning considering each other, couple's functioning considering the disabled child, and children's functioning considering each other. In general, it can be concluded that considering the significant statistics of disabilities in the country, the importance of examining marital challenges on various physical, mental, social and spiritual dimensions and the effects on the parents of adolescents with disabilities, the findings of this research study can be used in developing and strengthening counseling and support services for couples with disabled children. Specialists and service providers can provide solutions through the participation of family members in order to strengthen the informal social network, to increase the adaptability and health of these families, and to improve the quality of care given to the children. The results of the current research study are valuable due to their local nature and the use of a qualitative approach. However, one of the limitations of the current research is that this study was conducted in Tehran. Thus, it is suggested that samples from other cities be examined in future research studies. Furthermore, this study was investigated through a qualitative approach; other approaches, especially quantitative/qualitative (mixed methods approach), can be used to collect data. In order to prevent the severity of problems caused by disabilities and to improve the functioning of parents, it is recommended that parents be provided with some models and programs on communication training and psychological management.

Conflict of interest

There is no conflict of interest in this study.

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