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Spiritual experiences of family members to cope with the challenges of childhood disability: A Qualitative study in Iran

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Abstract:

BACKGROUND: If we take the family as a circle, the disabled child is in the center of the circle and weights on all communications in the family. Therefore, in this research, the experiences of all family members are studied. The knowledge about families' experiences helps the caregivers to have a deep recognition of family status and individual and social relations.

MATERIALS AND METHODS: This was a phenomenological study. Participants were Iranian families with disabled child and were selected by a goal-oriented sampling. Data collection was done through an unstructured interview. Interviews were transcript based. Data analysis was done by Colaizzi's method. Codes were extracted from the interviews and then the main concepts were formed by organizing the formulated meanings into clusters of themes.

RESULTS: Data were being compiled from the 18-h interview tapes and the verbatim transcription of the interviews with the 12 study participants. Then, the researchers formulated the meanings of each significant statement into 65 codes and organized the formulated meanings into following four clusters of themes: 1 – protective structure, 2 – adjustment, 3 – social isolation, 4 – psychological tension.

CONCLUSION: The existence of a disabled child may lead to psychological and spiritual distress and vast changes in every aspect of each member of the family.

Keywords:

Disabled children, experiences, family members, qualitative research

Introduction

With chronic illnesses and disabilities,^[1,2] the birth of a child with a disability is an event that has a dramatic impact on the family.^[3] Usually, family members try to cope with this event, but sometimes, they are vulnerable because of changes caused by the special needs of disabled children. Experiences and emotions of family members are unique and important. Knowing about these experiences could improve the chances of caregiving for emotional interactions among family

members of disabled children.^[4] The findings showed that some families never cope with the fact that their children have a disability.^[5] So far, parents are angry about this situation, they like their child, and then these psychological conflicts disturb their psychological health.^[6] If we take the family as a circle, the disabled child is in the center of the circle and weights on all communications in the family. Therefore, in this research, the experiences of all family members are studied.^[7]

It can support the family members to help themselves and their child and feel less

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unaided for changing the situation.^[8] The awareness about family's experience with a disabled child helps caregivers to get a deep detection of disabled child's family situation and personal and social relations. This process leads to discovering the effects of disability on family members, the problems due to disability, and the ways of adjusting. The problems following every disability in each family are unique; therefore, the qualitative aim of this study is to explore the Iranian families' experiences with disabled children and to reveal some aspects of these types of involvements.

Materials and Methods

This was a phenomenological study; phenomenology is a research method that investigates the opinion of people in humanistic issues; therefore, we used this method to understand the experiences of families having a disabled child. Purposive sampling using snowball techniques served as the mechanism to obtain participants for this study. To get research objectives, 12 members of the family were interviewed, including members who had a disabled child in their family and their child was kept in rehabilitation centers.

After taking the necessary permissions and introduction letters from the Isfahan University of Medical Sciences, the researchers introduced themselves and explained the aim and the method of data collection exactly for each participant and then obtained written consent of participants and assured them to keep their private data confidential. The interviews were conducted at the participants' home or their office. The researchers used an in-depth, unstructured interview (open-ended questions) to describe the concept of disability and meaning of disability; the researchers asked some probing questions to follow the conversation during interview and reviewed the data.

The researchers used observation notes and they took detailed notes for nonverbal attitudes. In each interview, the researchers asked about participants' experiences and asked subsequent questions according to the participants' responses. After the interview, the researchers reviewed the tape and noticed whether it was intelligible or needed to follow-up and asking other questions.

The data from this study were analyzed using seven steps in Colaizzi's methodology:^[9] (1) reading all of the participant's descriptions, (2) extracting the main phrases that directly pertain to the phenomenon, (3) formulating the meanings of each significant statement, (4) organizing the formulated meanings into clusters of themes, (5) formulating the exhaustive description of the investigated topic, (6) integrating themes into an exhaustive description of the phenomenon,

and (7) returning to participants and validating the descriptions from the data; if any new relevant data emerge, it will be included in the final research findings.

Methodological rigor was ensured through four techniques: trustworthiness, credibility, confirmability or auditability, and fittingness or transferability, as explained by Speziale *et al.*^[10] To assure the trustworthiness of the data, two study researchers studied codes, probed interviews, and validated them. Credibility enhanced through prolonged data collection and analysis over a 6-month period. In addition, three participants, in a follow-up discussion of findings, validated the descriptive findings of their experiences. For the conformability of the research, researchers demonstrated the procedures for checking the data throughout the study. To assure the similarity between determined codes and experiences of the participants, a member check method was employed.

Results

Data were being compiled from the 18-h interview tapes and the verbatim transcription of the interviews with the 12 participants: 8 females and 4 males. The age range of the participants was 26–56 years. Then, the researchers formulated the meanings of each significant statement into 65 codes and organized the formulated meanings into following four main clusters of themes: 1 – protective structure, 2 – adjustment, 3 – isolation, and 4 – psychological tension.

Protective structure

The first theme was "protective structure," and some formulated main phrases were "to love child," "to be upset for annoyed child," "support by family," and "to love child by relatives."

A father said about the family love for child: "when child was gone, all family was waiting for him to come back, and when he came back they showed their enthusiasm..."

Another father said: "I was worried about his future then I bought an apartment to be a resource for income..."

A mother said: "my family was encountered with a revolution, because the child needed more care than other children, and costs were higher."

"I knew he was different with other children therefore I considered him more!"

Adjustment

This theme comprised subthemes such as "individual attempts" and "spiritual attempts." Individual attempts

include defense reactions and attempt to change relative's behavior. Spiritual attempts include significant statements such as satisfaction of keeping the child, haunt with hope of treatment, God examination, gradually accepting by beliefs, family's prayer for child, and resorting to vow.

One of the participants said: "we restored vow and prayers." Then, the researchers extracted the "restoring to vow" code. Another participant who was a disabled child's father stated: "we believed the child was a divine Providence, and his/her problems were as a divine Providence, then according to my beliefs it was gradually accepted."

"I knew that all things were what God wanted. All family prayed for him" a mother said.

The third theme is "social isolation." It included five subthemes: humiliating the family by people, renunciation of relatives, to be remote of relatives, limited communication, and strange look of others.

A mother said: "our interaction with our relatives is reduced, specially our mother. We don't like to go anywhere, and we don't dare to tell someone our address..."

A brother explains his interactional problem: "I didn't tell to my friends that I have a brother and I hide his books."

"... I try to hide him of my friends. Thus I have little communication."

Psychological tension

It was a vast theme and included three subthemes: conflicts, subjective solutions, and family distress. The included codes are as follows: ashamed, guilt feeling, disturbing mind (busy mind and mentality disturbing), decreasing stress tolerance, showing excitement emotions, worrying, angry, feeling sorrow of dependent child, perplexity, disappointment, repugnance, be penitent for not accepting social support and feel fear to talk about their negative feelings, distress, exhaustion, conflict in accepting the child, child punishment, thinking about releasing of child, tend to rescue of life, rescue of situation, feeling of frustration in other children, not tend in siblings to communicate with the disabled child, distant relationship between siblings, and disturbance in sexual relationships.

One of the mothers in this study in relation to psychological tension theme said, "...when I believed that my child is disabled I felt disappointed, I didn't know what should I do, I was amazed for a while, I was worried." A brother indicated the disturbance in their family and said, "...

my sister was depressed she thought the disability of our brother affects her future." A sister said, "...I didn't like to see him, because I thought he was the reason of our misfortune and would be."

"... all family are tired. I can see exhaustion in my wife's face. Because the most of pressure is on her. Child has made many problems for family."

"... I'm ashamed because of having this brother and try to hide him of my friends. Thus I have little communication."

Discussion

In the case of parents, the birth of a child with disabilities is an intense and traumatic event. When it is learned at birth that the child is in some way abnormal, the effect on the parents can be devastating. Their initial reaction may be numbness. A parent's initial reaction is likely to be negative and similar to those related to bereavement.^[11]

The extended theme in this study is psychological tension that is, in many studies, repeatedly mentioned. Accepting disability of children and cope with this new situation is a continuous and psychological process. Based on the evidence, a common reason of anxiety and disappointment is to being forced to use of inadequate or inappropriate services. Parents should learn skills to take care of their children. They should learn some skills such as managing sleep disorders, interaction with children, supporting of psychological, and physical and social development of children^[12]. Furthermore, parents need diverse information^[13] in order to better adaptation, and more compatibility with their child, parents need professional protection.^[12] In this regard available support services such as consultants and good physicians to treat their problems are the top priorities of parents. Also, the health care team concerned with these challenges and issues could help parents in coping with disabled children needs.^[14]

In the present study, adjustment was one of the other extracted themes, which indicated that the family members had satisfied themselves through different modes such as frequent reference to the hope of treatment, accepting it as the divine test, and the gradual acceptance with the aid of their beliefs. Most of these adaptations are also observed in families of children with cancer.^[15] Godress *et al.* said that these types of feelings are physiological responses of family members to make adjustment with negative effects of the family member disability.^[16] In Arksey *et al.*'s study, the desire for siblings to make a positive adjustment was commonly raised by the parents.^[13] Despite the results of this study, some studies have showed the

disabled children not only does not have a bad effect on other members of families but also it leads to increasing tolerance and understanding among family members.^[17] Neely-Barnesin and Dia in a review article about families of children with disabilities stated that increasing in spirituality between family members not only is the result of having disabled children but also it leads to improving adjustment mechanisms. The family members use this spirituality to decrease the stress and cope with problems. Also, the authors commented that parents told that changes in philosophical and spiritual values are the most important aspects of having disabled children.^[18]

Social isolation is the other extracted theme. Extended personal and social networks and community involvement help families to cope with the new situation.^[19] However, the findings of this study as similar to Lauver's study showed that families have limited their communications with external world.^[1] However, using of experiences of other families could be valuable to manage their problems. Experiences are informative; therefore, planning for interactions could be according to them. And, successful families can help health providers, not only about what work, so that they could support who are struggling, but also about their opinion toward the families with disabilities.

Protective structure was one of the other themes derived from the family members' experiences, especially the parents. In this regard, secure financial future of a child with special needs was the matter that has worried parents. In other studies that investigated the financial issues related to disabled children, the results showed that worrying about costs of caring has correlation with stress in families, and when the families have more salary, they are more healthy.^[12,14,19]

Psychological, social, and financial problems that family members experience in living with disabled child can result in conflict or change the relationship between family members and their function in family.^[12] Usually, fathers take care of healthy children and mothers take care of disabled children.^[13] A mother is a person who changes her life for children and usually she is the first caregiver of her children.^[15] A phenomenological research by Barbosa *et al.* about mothers' experience showed that the disability of child may cause grievous process and conflicts for mothers so they feel they are not prepared for being a mother.^[4] This study confirmed that when the situation of child is worse, family members are worry about disabled children, and when there are some limitations for moving, we can see some disorders in family functions and these supportive activities are defined in a protective, structured theme. Therefore, we should be sensitive and informed when providing cares for families with disabled children.

Conclusion

The child with disability may lead to psychological tension and vast changes in every aspect of the family and their interaction as well. The family members take different adaptation ways to catch up and return to normal life. In spite of psychological and spiritual conflicts they are faced with, parents try to protect their child; in some cases, these adjustments do not occur properly such as hiding the child from the society to protect the family. Anyway, it is a crucial support and training centers should be established for disabled children's families facing emotional problems and assistance in more effective adaptation.

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Conflicts of interest

There are no conflicts of interest.

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