

# How parents cope with the care of a child with epilepsy: Based upon grounded theory

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## Research article

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# Abstract

**Abstract:** parents of children with seizure have to face the complicated health issues of their children. Coping strategies of parents as major care providers impact not only their handling of stresses on themselves, but also the children's quality of life. This study investigated the coping processes of parents of children with seizure at two educational hospitals affiliated with the Kerman University of Medical Sciences in Iran.

**Method:** Twenty parents (15 mothers and 5 fathers) and three nurses were selected using the purposive sampling method. Data was collected using qualitative semi-structured interviews and analyzed using the method suggested by Corbin and Strauss. Interviews were conducted until thematic saturation was achieved.

**Results:** The adaptation process had five phases: "Disbelief, Patience on what happened, patient on what happened, change to preserve, and acceptance of the current situation by the parents and her child and empowerment". In summary, parents of children with seizure have a 5-phase coping strategy. Core category is achieved "continued efforts of parents to restore calm".

**Conclusion:** Properly assessing the stresses on parents of children with seizure and their coping strategies may help medical staff and social services provide more targeted support and promote the balance of the family function.

# Background

Epilepsy is the most commonly diagnosed chronic disorder of the nervous system(1). It is characterized by the individual's ability to suffer from seizure and two or more self-inflicted attacks. The disease is a threatening condition and a medical emergency that results in a high percentage of morbidity and death (2). Additionally, epilepsy is one of the most common chronic neurological diseases in childhood and is one of the significant health problems in different countries(1). The point prevalence of active epilepsy was 6.38 per 1000 persons, while the life time prevalence was 7.60 per 1000 persons. Due to recent advances in medical science and technology, the prevalence of chronic and impaired seizures in the pediatric population is increasing (3). In Iran, 4.2 out of every 1,000 school children have epilepsy, and 65% of patients with epilepsy are children and teenagers (4). The unpredictable and chronic nature of epilepsy can affect the physical and social health of the patients and his or her family. Epilepsy is often associated with psychosocial problems (5) because of its long-term nature. The quality of life of people with epilepsy is lower than that of the general population, and it is less or worse in comparison with the quality of life of other patients, such as those with asthma and diabetes (6). It ultimately leads to problems such as lack of self-esteem, depression, anxiety, social isolation, and fear of death at the time of the attack (7). According to the literature review patients with epilepsy face physical and mental problems. Reily 2014 reported Epileptic patients are likely to face stigma, with a sense of disgrace, and leads to social isolation. In 20% of patients with epilepsy, depression has occurred observed, and the

suicide risk in them is two times that of the healthy population (8). In the study of Thomas S and Reilly c Hyperactivity (9) cognitive disorders and depression (10) are observed in patients with epilepsy. Although many patients with epilepsy have normal IQ, in general, they are weaker in cognitive functions such as difficulty in attention, thought process, finding correct words and memory problems than healthy people (8). Jones C 2016 found, Epilepsy is considered to be a crisis for the whole family and should be supported to adapt to epileptic attacks. Because the child's parents judge themselves responsible for their illness and feel anxious, guilty, and it ultimately affects the whole family's performance (11).

Also, it causes some problems for the parents. For instance negative attitudes toward themselves, behavioral disorders, confusion, fear about the attacks. In addition, they were thinking about the uncertain future of the child (in terms of education, occupation, and marriage), fear of psychological and emotional problems in the child. They have financial difficulties caused by the cost of treatment, fear of having another child with epilepsy, fear of complications of medications and injuries during the seizure. All these issues and problems are influential in depression and anxiety of the patients' parents (12). Studies show that there are more anxiety and depression among the families that have patients with epilepsy. Families said that "their misfortune is equal to or even greater than the patient's experience" (13). Parents who take care of the epileptic child are emotionally injured, and their sexual desire is decreased. Caregivers of epileptic children may hesitate to spend time away from home because of the fear that the child may have an attack at any moment, and the home environment can provide a secure structure, and therefore families are more likely to spend time at home (14). Previous studies have investigated only one dimension of the life of the parents of children with seizure, and according to the review of the literature, no study was found regarding the adaptive process of parents of children with seizure. Also, parents' adaptation process depends on their attitude, level of education, their own culture, and the number of resources available. Deep understanding of parents' adaptation process helped the health professionals to identify the needs of these children and their families. In this article, we use a qualitative grounded theory approach to examine the process of adaptation of parents of children with seizure.

## Methods

The current study was done using a qualitative approach, and grounded theory for identifying adaptation process of the parents of children with epilepsy. Grounded theory methodology has been an integral part of health social science. It allows for the systematic collection and analysis of qualitative data to inductively develop middle-range theories to make sense of people's actions and experiences in the social world (15).

Qualitative grounded theory is an appropriate method to obtain variable and reliable results from textual data. This method is used to create new Knowledge and ideas, and provide context based facts and guidelines, aiming to condense a broadly described phenomenon, with achievements of deep understanding of the phenomenon (16).

### *Research Design and Setting*

This study was conducted in Kerman, Iran, from June 2016 to October 2018. The city of Kerman is located in the southeastern part of Iran in an area with cultural diversity and mixed ethnicity. The extent of Kerman province, the dispersion of its population, and the high prevalence of epilepsy in this province in conjunction with deficiencies in healthcare services caused the parents of these children faced many problems. In this study, participants included parents of children who have epilepsy coming to the specialized neurological wards of two educational hospitals affiliated with Kerman University of Medical Sciences, to which patients with the epileptic disease.

### *Participants and Sampling Method*

Purposive sampling was used to select participants for this study. The population comprised 15 mothers and five fathers of children with epilepsy admitted to hospitals affiliated with Kerman University of Medical Sciences, Iran and three nurses working in the neurology and pediatric wards (Table 2).

The researchers attempted to observe maximum variations in terms of demographic characteristics (numbers of child, level education and economic) and type of epilepsy. The researchers also tried to interview knowledgeable parents who could deliver broad insight into their responses to the study question. Inclusion criteria included the ability to speak the Persian language, the child's age being between one year and 14 years, diagnosis of child's disease at least one year previous to the study, and the participants' willingness to participate in this study. Exclusion criteria were cognitive impairment confirmed by a psychiatrist.

### *Data Collection*

Data was collected through face-to-face, interviews conducted by a PhD in nursing that was a research team member. Team members were three assistant professors and a BSc student of nursing. Interview locations and times were agreed upon by both the interviewer and the interviewee. Written and verbal consent was obtained from each participant by the researcher.

First, the researcher told the participants about the study aims and explained its benefits. Then, based on the study's objectives, general questions were raised. Several examples are as follows: how do you manage your sick child? Please, explain one day of care for your child? How do you solve your problems? (table1).

The interviews were conducted either at the hospital or the home of the participant and lasted between 30 and 90 minutes, with an average duration of 60 minutes.

### *Data analysis:*

In the present study, grounded theory method used. For analysis, using grounded theory Corbin and Strauss version 2008. First, the first author listened to the recorded interviews 4–5 times. In the next step,

the whole conversation was typed word by word in a Microsoft word document and analysed using MAXQDA software 10. The interview was transcribed and regarded as a unit of analysis. Some texts were reviewed by the same interviewee and corrected if necessary. For better understanding, every finalized document was read by one of the members of the research team and the meaning units were extracted. The meaning units were categorized and summarized based on similarities and differences, and the meaning codes were extracted. According to the degree of relatedness among meaning codes, they were classified into subcategories which represented the same subject. The assessment of interrelations among subcategories was done, and the main concepts were extracted from them. At the end of each step, the core category extracted and discussed among research group members. The final findings were discussed with the participants in a meeting, and their last remarks were received.

### *Ethical Considerations*

Ethical considerations were addressed before the study began. All participants completed written informed consent forms and were assured that their information would remain confidential. This study was approved by the Ethics Committee of Kerman University of Medical Sciences (IR.KMU.REC97000448). Study purposes, the confidentiality of data, and recording of interviews were clarified for the participants before their interviews, and their verbal agreements were obtained.

## **Results**

Of the 23 study participants, fifteen mothers, five fathers of children with epilepsy, and three nurses were interviewed. The Interviews were conducted twice for three mothers (26 interviews in total). The range of age for participants was 28–52 years (average  $33.5 \pm 2.2$  years). The interviewed parents all had children with epilepsy problems of different degrees of intensity and at various stages of treatment that were being treated in public health centers.

After analyzing the data, strategies of parents in living with children suffering epilepsy was described.

In this study, parents of children tried to prepare an excellent situation for their child. They were using all available resources. Although the lack of resources and support as well as their child's care were excessive burdens on them, they resolved these problems by searching for different strategies and using them to manage care for their children in a peaceful state and to get the best results.

The adaptation process had five phases: *Disbelief, Patience on what happened, change to preserve, and acceptance of the current situation by the parents and her or his child, self-empowerment.*

In summary, parents of children with seizure have a 5-phase coping strategy. Core category is achieved "continued efforts of parents to restore calm."

1. *Disbelief*: the parents of these children did not believe their child's disease. This category consisted of three subcategories "Denial of the child's illness, Escape from reality, looking for guilt."

### *1.1. Denial of the child's illness*

Almost the parents of these children, in the first phase of the diagnosis of disease, did not believe their situation. They did not accept the child's illness for a long time. Participant no.23 said, "After the diagnosis, I did not believe that. I took my child to this doctor and that doctor. Maybe one of them rejected the diagnosis. My husband told me, "This child did not have any problem. He is healthy. Not take him to the doctor".

### *1.2. Escape from reality*

Some of the parents did not follow to treat their sick children. They did not do anything about the definite diagnosis and treatment. They were not able to accept their child is sick. They often referred to the time that the child's condition was terrible, and the symptoms of the disease were aggravated.

This subject caused more severe psychological complications for the family and made the treatment more difficult and complicated.

Participant no.21 said," some parents did not want to accept their child' disease. They did not want to accept reality. They wanted to achieve new things. A new diagnosis, a new work. For this reason, they changed the doctor.

### *1.3. Looking for guilt: feeling guilty and guilty of participants, after the definite diagnosis, the parents sought to find the culprit behind their child's problem.*

Participant no 5 said, "I told God, what you do my god, what did you get from this kid? In the night of winter, I swore allegiance to God. I said," If I'm guilty why my child.you have to punish me."

*2. Patience on what happened:* Almost all of the participants in this experiment tried to be patient throughout every stage of their children's illness and treatment; they tried to tolerate the tension inherent in the situation.

*2-1.tolerant care:* The parents patiently nursed their sick children at all stages and endured many hardships during their child's illness. Participant No. 4 said: "When I was breastfeeding my child, I did not rush him to suck and drink faster, because he didn't have enough strength to suck and he was breathing slowly. So I breastfed him slowly, or I would take my breast out of his mouth and wait two minutes, and give my breast back to him."

Participant no. 10 said: "Because of my bad financial situation, it took a while for me to take my child to the hospital, which was tough. I wouldn't buy anything to save money. I was so worried, but I couldn't do anything except wait to save enough money to hospitalize him. It was challenging".

*2-2: endure of great sufferings:* in this study, all the parents mentioned directly or indirectly the problems that they had to face, and the burdens that they carried throughout this period. For example, participant no. 1 said: "I locked myself up at home for at least six months, because I didn't want my child to be

exposed to any disease, and if I attended even a small party, I would make sure that no one had a cold. I wouldn't let anyone hug or kiss my child, because the doctors kept saying that my child is much weaker than other children. I've been through a lot to keep him away from getting sick." Participant no. 6 said: "I had a difficult situation last year because my child's situation wasn't clear. I didn't know what to do with him when I got to work. When I wanted to take him to kindergarten, it was very hard for him to wake up in the morning. He would cry and be annoying. It was a hard time. I did not know what to do. I don't want to experience those days again".

*3. Change to preserve:* In this study, change to preserve included two sub-themes: first, imposing the pressure of the situation on oneself, and second, changing the life routine.

*3-1. imposing the pressure of the situation on oneself:* Parents experienced a tough and difficult situation after their child fell sick. They had to endure some problems related to this particular condition. They had no choice but to accept their child's illness, his/her abnormal situation, and his weakness and limitations. In many cases studied here, parents had to endure some problems, because there were no other solutions to the problem or because they were unable to do anything other than tolerate the situation. Participant no. 13 said: "When I went to visit my child's pediatrician, I asked him what I could do. I would usually listen to anything he said. I had no other options; I had to. I preferred to listen to him." Participant no. 9 said: "My husband could not bear to see our child. He was so scared that something will happen to our child during hospitalization. He kept calling and asking about him, but he never came to the hospital. I didn't have any choice; I had to take my child into the operation; otherwise, I would have lost him ". Participant no. 6 said: "For a few days when I took my child to kindergarten in the morning, her teacher would say that she would not give her medicine. I had to wake her up early in the morning and give her the medicine, then take her to kindergarten. Normally I would have never awakened her from his sleep, even if I had an important job to take care of. I would let her sleep". Participant no. Seven said: "Early in my child's disease, I could only get two hours of sleep during the day because of his bad condition. You may not believe me, but those two hours were enough for me, though I was exhausted". Participant no. 2 said: "I always made healthy, nourishing food for my child. I had to make it. It was my responsibility. I forced myself to make fresh food for him every day".

*3-2. Changing the life routine:* Because of their child's illness and need for care, the parents tried to adjust their life to give themselves more opportunities to spend time with their child, even if they had to leave her education or her job. Participant no. 6 said: "I was so scared that something would happen to my child at kindergarten. Finally, after thinking a lot, I decided to consult with her doctor. Her doctor wrote a letter for my workplace that my child couldn't be left at kindergarten and that due to her special condition and problems, emotional attachment, and psychological dependence, she may get hurt. So I got three years of unpaid leave." Participant no. 5 said: "After my child got sick, I couldn't work. Since my job was in the private sector, I couldn't get leave, so I lost it." Participant no. 3 said: "I dropped out of school because I couldn't go to school and take care of my child at the same time. He wasn't a normal child."

4. *Acceptance of the current situation by the parents and her child:* In this study, acceptance of the situation consisted of two sub-themes: *acceptance of the child's situation by the parents* and *acceptance of the parents' limitations by the child*.

4-1. *Acceptance of the child's situation by the parents:* The stage of accepting the illness, inabilities, and limitations that come with living with a sick child began for the parents after some emotional ups and downs. After quite a while, the parents learned not only to accept their child's condition but also to help the child adjust to his/her situation. Participant no. 4 said: "My child should not run or play football. He asks me to take a taxi after walking for a bit. He is not a normal kid. He is weak and can't be as active as his peers. I should make a comfortable situation for him to live." Participant no. 3 said: "Even when we go to a wedding, we return home very early or I stay home with the child because she gets so tired later at night. I don't want any pressure or stress on her. She is not a normal kid; she needs special care. When she gets upset or angry, her appearance was changed."

4-2. *Acceptance of the parents' limitations by the child:* Usually, sick children realize their inabilities to perform some tasks by the age of 5-6 years. When they face shortness of breath or lack of physical strength, and at the beginning of seizure attack, they can manage themselves, quite the task at hand, and went to a safe place. They cooperate well with their mothers and fathers in this matter, especially those mothers who always speak to their children, give them instructions, and educate them regarding their situation. Participant no. 10 said: "My kid cannot run or play for a long time. He gets shortness of breath soon. When he goes to a playground, he doesn't run a lot; he goes up and down a slide and then sits. He knows very well that he can't run anymore at that moment, or he says, 'mom I'm tired.'" Participant no 2 said: "When he goes to play with other kids, he takes them home to play Ludo or computer games instead of going out to run with them. He realizes that running makes him feel bad, so he encourages his friends to play the games that he can play."

5. Self-empowerment: Self-empowerment in this study included self-empowerment of the children order to perform self-related caring activities and usage of resources and possibilities by parents for the self-empowerment of themselves.

5.1. Self-empowerment of the child: children usually became aware of their limitations from 5-6 years old, and they could manage the situation when they face problems such as shortness of breath or lack of physical vigor. In these situations, they would stop their activity and try to engage another game. They were using matters which parents have taught them. Mental preparation which their mothers are created caused the Children had more corporation with parents. They always talked to their child about methods of self-protection and provided necessary training to them.

Participant (13) expressed: "my child always knows when he should rest, when he is running or which activities will make him feel bad. I have ever trained him. I tell him not to do some exercises. I provide information to him. I always say to him lets search together. I still talk to him and remind him about care tips".

Participant (14) expressed: " I have always told him which activities would be harmful to him using different methods from the age of 4–5 and that he should be careful. I trained him according to his cognitive age, and I do this now too. Now he can search for things related to his disease or problems which have shaped up in his mind because he has gotten older and he always searches for the answers of questions in the field of his illness".

5.2. Self-Self-empowerment: parents in this study can try for the self-empowerment of themselves using resources and facilities which exist for caring of the child. They tried to provide useful and practical cares using consultation with professional people (nurses, doctors), the application of inventiveness, obtaining information from intelligence sources (books, internet) and using others' experiences.

Participant (6) expressed: " My husband and I visited Psychologist a few times before because we felt we should have proper behavior toward the child. I asked my questions from Psychologist about what should I do with this child and how should I behave so that he does not become capricious and also will not have stress. I paid attention to the recommendations of the psychologist and carried out all of them.

Participant (4) expressed: " I always consulted with nurses, and I asked them the proper method of giving medicine to my child and their behavior with the child was exemplary for me."

Participant (6) expressed about using ingenuity and creativity in care: " If I see that he likes two things, I would say to him, listen you have done that good thing today, and I will give you this because of that good thing you did. This way, he is encouraged to do good things".

Participant (5) expressed: " I would hug her when she ran a lot or did a lot of activities. I always explained to her that running a lot is bad for you, you would feel bad, and I would make her up to look pretty. I would always talk to her and convince her that she should not do some activities".

Parents in this study used newspapers, books, or the Internet based on their education level to manage the disease of their child.

For example, Participant (4) expressed: " I try to study books for any questions that I would have whether it is mentally or it is about drugs' complications or the disease of my child form books that I have or even from the internet. I borrow different books about the illness of my daughter form my work, and I read them".

Participant (20) expressed: " I studied a lot, I would read the book to find out what I should do with him. I read books about the age of my child and got some information on the internet. I was cautious with his nutrition. I would cook nutritious foods with turkey meat and ..."

Participant (13) expressed about using their own and others experiences: " because I had experienced Teucrium polium and was right for me, I have it to him too."

Participant (2) expressed in this regard:” when my child was hospitalized, I always went to other rooms of the hospital to see if my child has the worst conditions or other kids. I met other mothers there. Talking to them somewhat made me calm, and at the same time, I learned a lot of things from them. I would use their help if I had any question.

Participant (13) expressed:” I have met some other mothers whom their child has the similar disease as my child, and we were in contact with each other by phone, and we provide calmness for each other, and if we have any questions, we ask each other.”

Two of the mothers in this study had similar experiences with the disease which had passed the treatment process. The difficulty of caring for these mothers was a lot more than the mothers who were not sick.

Participant (14) expressed in this regard:” I had this disease. I was challenging. I can remember how many problems. I endured hardships but I could understand the feelings of my child. I knew what to do for him. Which food I should give to him and how to take care of him. Although it was hard, I think now I can understand my child better than other mothers because I have had the experience of this disease and for this, I could take care of him better”.

## Discussion

A total of 23 participants (26 interviews) participated in the study. Fifteen were mothers of children with epilepsy, 5 were fathers, and three were nurses of the pediatric ward. Interviewed parents had children with epilepsy disease in different types and they were under treatment with various medicines. Disbelief, change on what happened, Change to preserve, Acceptance of the current situation by the parents and her child, self-empowerment appeared by analyzing data.

In this section, the available scientific evidence on the importance of codes will be discussed. Although a few qualitative articles were found, we try to use both qualitative and quantitative studies in the discussion.

Facing a child’s disease is a crisis for parents, especially for the mother, because she expect to have a healthy child but suddenly encounter a lot of stress after hearing about their child’s illness (17). The parents’ first reaction is to deny the child’s disease. Feeling guilty and looking for something to blame is another reaction of parents early on after diagnosis (18, 19). A child’s illness reflects not only the parents’ but the whole family’s life from its typical path. In this challenging situation, parents do their best to adjust themselves and their families to the new situation using any available methods to provide a relatively healthy life as much as they can. Family members play a crucial role as supporters of the patient in helping them adjust better and faster to the conditions of the illness (20). In Iranian culture, parents have the strongest bonds with their children; therefore, their efforts to improve the living conditions of children are advantageous. In developing countries like Iran, all facilities will be used to improve the physical health of a child who is suffering from a chronic illness. However, the successful

adaptation of the child's family, especially mothers, has a positive impact on a child's faster recovery (21). Parents try to increase their resistance and tolerance against the concerns and worries that exist throughout all stages of the illness, from the diagnosis time to the treatment process. Parents have different levels of tolerance and mental capacity (22). In this study, some parents were more restless than others. For some of them, coping with the situation was not getting more comfortable with time. For example, some parents were still asking themselves why them, why their child even after three or four years of illness. They hadn't accepted the situation. Each one of the participants said that they are putting forth all their effort to be patient when dealing with the problems. All the participants in this study were Muslims who believe in patience. They considered religious teachings to be life principles which suggest that human beings must have patience in the face of tragedy and problems and that what God wills will happen (23). Among the parents in this study, those who had stronger religious beliefs were more calm and relaxed. The majority of the parents increased their mental capacity and patience by going to mosques and attending spiritual programs. Previous studies have also found that families consider praying and going to church a way of finding peace (22, 24). Whaley and Wong pointed out the fact that by relying on religious philosophy, families believe that every problem is a way to further grace and faith (23). All the parents who participated in this study had experience the patient. They would engage in anything related to their child, from feeding them to reacting in front of them calmly and carefully. In a study of parents' adaptation strategies for Chinese children awaiting a liver transplant, prudent care was represented as an experience by their parents (24).

Concerning the illness and treatment of parents with financial difficulties, problems regarding managing physical symptoms beside performing the duties of their jobs, a lack of knowledge about nursing and methods of caregiving, and the compulsion to send their children to kindergarten were listed as the most challenging problems in managing patients with heart disease in both this study and similar others (25–29). Illness is indeed accompanied by significant physical and emotional difficulties for the sick child's family, especially for the mother (30), but these difficulties can be reduced through emotional support given to these families (31). The behavioral support of treating staff members is more like emotional support. They also provide information regarding how to manage the illness and the patient's condition. Patients and their families expect staff members to give them attention as well as data (17, 32). Teaching the correct ways of using available resources, informing mothers about the treatment process, understanding the disease, referring mothers to financial support centers, and forming support groups of mothers of children with similar disorders are things that nurses can do to help these families adjust faster. Borji, in his study, suggested that nurses should train information in the field of self-care in adolescents with type 1 diabetes(33).

When these mothers get together, they empower themselves to manage their sick children rather than doing it individually. Having a nursing staff knowledgeable in life skills training and empowering mothers (18) to help them manage and control the situation is one fundamental need of mothers in Iran. The performance of effective nursing interventions (19) and the availability of nurses at all hours, especially at times when the child feels sick is important to adapt faster. Several studies have shown that remote nursing systems are significantly effective on creating peace and improving the mental state of chronic

patients and their families, reducing financial costs, eliminating problems regarding long distance trips, reducing of the number of patients referring, and improving patients' quality of life (20). Encouraging parents to take care of themselves while also nursing their children by reminding them that if they are healthier, they will be able to provide more quality care to their children is another thing that nurses should consider when interacting with these mothers. The results of some experiments suggest that the health of parents has a significant effect on the physical and psychological recovery of their sick child (21). Providing conditions for schools and kindergartens to collaborate more (in the presence of nurses with academic studies) will allow the children to spend a few hours with their peers. This is significantly effective in giving mothers peace of mind and in boosting the well-being and happiness of the children. Cases of stress, anxiety, and depression are higher among children with chronic diseases compared with healthy children (34). Therefore it is necessary to consider their psychosocial health as well as their physical health (35). Psychosocial care planning for this group of children will be available with a secure support system and effective, accompanied by the family of the child. Educating the children and their families in how to communicate and live with their peers can reduce the number of problems for this child (34). In this study, parents were dealing with the issue of coordinating work hours with nursing their sick children so that some of them had to leave work to take care of their patient. However, if conditions in which they could work part-time or perform their job duties at home could be provided, they will be helped to tolerate the situation better, and their mental strength will be increased. The improved maternal mood can help these mothers adjust faster to the harsh conditions of childcare. According to some studies, a job for the mother leads to greater independence, a sense of self-empowerment, enhanced care and commitment, and a longer life expectancy (35). However, in the course of child disease diagnosis, Iran faces a lack of resources; therefore, families manage to take care of their children with no spiritual, social, or financial support, which in return reduces the quality of life of those children's mothers and fathers' (36). As the quality of life of the parents comes down, optimal care and the quality of nursing also decreases (37). The parents, in the process of nursing their sick children, changed the conditions of their life in a way that assists them in taking good care of their children, even though they had to tolerate some problems such as difficulties with giving medicine to their children or their child's fussiness. In other cases, they used specific innovations to improve their child's condition, such as connecting with their child's peers to ask them to take care of their children at school or purchasing brain games which do not require physical activity.

In most cases, mothers could deal with the situations created by the disease. For instance, they said that they are in a better mental state in the surgical stage or follow-up stage, after going through the crisis and facing the severe conditions (38). In this study, the parents of these children try to adapt themselves to their situations by doing particular behaviors. Deep understanding of adaptation process can help nurses to complete the identification of the needs of these children and their parents, and enables nurses to be more aware of the proper management of the disease. Therefore, parents feel more support, gain more knowledge and information. achieve faster adaptation and consequently, more accurate care. Also, a deep understanding of the methods of compatibility can be used to promote the lives of other children and help parents for providing proper care.

In the current study, after passing different stages of stress and anxiety during diagnosis and treatment, the families and the sick children concluded that they should accept and get used to the disease, disabilities, limitations, and repeated visits to doctors.

## Conclusion

The current study is a grounded study. The methodology enabled investigators to obtain detailed information from the subjects and offer phenomenal explanations. This approach can also unravel answers and lead to a better understanding of existing issues. This study found that parents play a critical role in the care of children with seizure, and they face multiple challenges. It was found that the mothers and fathers in this study went through five phases of coping with their situations and applied coping strategies to minimize stress or reduce familial conflicts. Furthermore, determining parents' coping strategies will help provide families with targeted interventions to improve family function. Also, the nurses and physicians understand about the path of adaptation process. Additionally, they achieved information about the needs of these children and their parents by this study, and helped them to solve their problems.

## Limitations Of The Study

Despite the mechanisms applied to enhance the rigor of this study, some restrictions may be inherent. The sample size was small, and the context was confined to a particular geographic location. However, the study offers some valuable insights into the ways that parents' cope with their situations. The findings of this study are transferable to other parents of deceased children and pediatric nurses.

## Declarations

*Ethics approval and consent to participate.*

The Ethics Committee of the Kerman University of Medical Sciences accepted this study with the code No: 97000448. All the participants were informed about the study's objectives by the researchers. The participants were assured that their information would remain confidential. Written informed consent was obtained from the participants.

*Consent for publication*

Not applicable.

*Availability of data and materials*

The data sets generated during the study can be shared publicly because it does not contain information that could be traceable to specific participants.

*Competing interests*

The authors declare that they have no competing interests.

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### *Conflicts of Interest:*

the authors of this study declared no conflict of interest

### *Author contribution*

This manuscript is the consequence of the collaboration of all the authors. Author MN designed the study, wrote the study proposal, conducted interviews, and analyzed the data. The author RM analyzed the written interviews, and the Author BB wrote the final draft of the manuscript, prepared tables, and submitted the document to the journal. The author FK conducted the interviews and transcribed the interviews.

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## **References**

1. Reading R, Haynes R, Beach R. Deprivation and incidence of epilepsy in children. *Seizure*. 2006;15(3):190–3.
2. Cole C, Pointu A, Mahadeshwar S, Dudley A. Community Survey of Carer's: Individual epilepsy guidelines (IEG) for rescue medication. *Seizure*. 2009;18(3):220–4.
3. Hockenberry MJ, Wilson D, Rodgers CC. *Wong's Essentials of Pediatric Nursing-E-Book*: Elsevier Health Sciences; 2016.
4. Masoud SA, Kochaki E. Surveying the family attitude of a patients with epilepsy hospitalized in Shahid Beheshti Hospital in Kashan, 1378–79. *KAUMS Journal (FEYZ)*. 2004;8(1):79–86.

5. O'Toole S, Benson A, Lambert V, Gallagher P, Shahwan A, Austin J. Family communication in the context of pediatric epilepsy: A systematic review. *Epilepsy & Behavior*. 2015;51:225–39.
6. Cianchetti C, Messina P, Pupillo E, Crichiutti G, Baglietto MG, Veggiotti P, et al. The perceived burden of epilepsy: impact on the quality of life of children and adolescents and their families. *Seizure*. 2015;24:93–101.
7. Berg AT, Baca CB, Rychlik K, Vickrey BG, Caplan R, Testa FM, et al. Determinants of social outcomes in adults with childhood-onset epilepsy. *Pediatrics*. 2016:peds. 2015–3944.
8. Reilly C, Atkinson P, Das KB, Chin RF, Aylett SE, Burch V, et al. Neurobehavioral comorbidities in children with active epilepsy: a population-based study. *Pediatrics*. 2014:peds. 2013–3787.
9. Thomas S, Hovinga ME, Rai D, Lee BK. Brief report: prevalence of co-occurring epilepsy and autism spectrum disorder: the US National Survey of Children's Health 2011–2012. *Journal of autism and developmental disorders*. 2017;47(1):224–9.
10. Reilly C, Atkinson P, Das KB, Chin RF, Aylett SE, Burch V, et al. Cognition in school-aged children with “active” epilepsy: a population-based study. *Journal of clinical and experimental neuropsychology*. 2015;37(4):429–38.
11. Jones C, Reilly C. Parental anxiety in childhood epilepsy: a systematic review. *Epilepsia*. 2016;57(4):529–37.
12. O'Toole S, Lambert V, Gallagher P, Shahwan A, Austin JK. Talking about epilepsy: challenges parents face when communicating with their child about epilepsy and epilepsy-related issues. *Epilepsy & Behavior*. 2016;57:9–15.
13. Painter E, Rausch JR, Modi AC. Changes in daily activity patterns of caregivers of children with newly diagnosed epilepsy: a case-controlled design. *Epilepsy & Behavior*. 2014;31:1–6.
14. Mu P-F. Transition experience of parents caring of children with epilepsy: A phenomenological study. *International Journal of Nursing Studies*. 2008;45(4):543–51.
15. Belgrave LL, Seide K. Grounded Theory Methodology: Principles and Practices. *Handbook of Research Methods in Health Social Sciences*. 2018:1–18.
16. Charmaz K. *Constructing grounded theory*: Sage; 2014.
17. Helgeson VS, Becker D, Escobar O, Siminerio L. Families with children with diabetes: Implications of parent stress for parent and child health. *Journal of pediatric psychology*. 2012;37(4):467–78.
18. Burns T, Fernandez R, Stephens M. The experiences of adults who are on dialysis and waiting for a renal transplant from a deceased donor: a systematic review. *The JBI Database of Systematic Reviews*

and Implementation Reports. 2015;13(2):169–211.

19.Popp JM, Robinson JL, Britner PA, Blank TO. Parent adaptation and family functioning in relation to narratives of children with chronic illness. *Journal of pediatric nursing*. 2014;29(1):58–64.

20.Ali MM. *The religion of Islam: Ahmadiyya Anjuman Ishaat Islam Lahore USA*; 2011.

21.Hawthorne DM, Youngblut JM, Brooten D. Parent Spirituality, Grief, and Mental Health at 1 and 3Months After Their Infant's/Child's Death in an Intensive Care Unit. *Journal of pediatric nursing*. 2015.

22.Franck LS, Mcquillan A, Wray J, Grocott MP, Goldman A. Parent stress levels during children's hospital recovery after congenital heart surgery. *Pediatric cardiology*. 2010;31(7):961–8.

23.Schoonewille HH, Heijstek W, Chaudron MR, Kühne T, editors. *A cognitive perspective on developer comprehension of software design documentation*. Proceedings of the 29th ACM international conference on Design of communication; 2011: ACM.

24.LINDBLOM AK, BÄCK-PETTERSSON S, Berggren I. A quality registers impact on community nurses' in end-of-life care—a grounded theory study. *Journal of nursing management*. 2012;20(2):206–14.

25.Liu Z, Yu D, Zhou L, Yang J, Lu J, Lu H, et al. Counseling role of primary care physicians in preventing early childhood caries in children with congenital heart disease. *International journal of environmental research and public health*. 2014;11(12):12716–25.

26.Olsen M, Sørensen HT, Hjortdal VE, Christensen TD, Pedersen L. Congenital Heart Defects and Developmental and Other Psychiatric Disorders A Danish Nationwide Cohort Study. *Circulation*. 2011;124(16):1706–12.

27.Rychik J, Donaghue DD, Levy S, Fajardo C, Combs J, Zhang X, et al. Maternal psychological stress after prenatal diagnosis of congenital heart disease. *The Journal of pediatrics*. 2013;162(2):302–7. e1.

28.Lee S, Yoo J-S, Yoo I-Y. Parenting stress in mothers of children with congenital heart disease. *Asian nursing research*. 2007;1(2):116–24.

29.DeMaso DR, Snell C, editors. *Promoting coping in children facing pediatric surgery*. Seminars in pediatric surgery; 2013: Elsevier.

30.Östman M, Ung EJ, Falk K. Health-care encounters create both discontinuity and continuity in daily life when living with chronic heart failure—A grounded theory study. *International Journal of Qualitative Studies on Health and Well-being*. 2015;10.

31.Holloway I, Wheeler S. *Qualitative research in nursing and healthcare*: John Wiley & Sons; 2013.

32.Anselm S, Corbin J. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. SAGE Publications, Thousand Oaks, USA. 1998.

- 33.Kazeminezhad B, Taghinejad H, Borji M, Tarjoman A. The Effect of Self-Care on Glycated Hemoglobin and Fasting Blood Sugar Levels on Adolescents with Diabetes. *Journal of Comprehensive Pediatrics*. 2018(In Press).
- 34.Zahmacioglu O, Yildiz CE, Koca B, Ugurlucan M, Gokalp S, Cetin G, et al. Coming from behind to win-A Qualitative research about psychological conditions of adolescents who have undergone open-heart surgery for single ventricle between the ages 0–5. *Journal of cardiothoracic surgery*. 2011;6(1):1–8.
- 35.Mousavi SA, Ajang F, Khazaei H, Paveh BK. Comparison of life quality in mothers of children with cerebral palsy and normal children. *Journal of Kermanshah University of Medical Sciences (J Kermanshah Univ Med Sci)*. 2014;18(9):532–8.
- 36Lawoko S, Soares JJ. Quality of life among parents of children with congenital heart disease, parents of children with other diseases and parents of healthy children. *Quality of Life Research*. 2003;12(6):655–66.
- 37.O'Hare D, Helmes E, Eapen V, Grove R, McBain K, Reece J. The Impact of Tic Severity, Comorbidity and Peer Attachment on Quality of Life Outcomes and Functioning in Tourette's Syndrome: Parental Perspectives. *Child psychiatry and human development*. 2015.
- 38Dadipoor S, Haghghi H, Madani A, Ghanbarnejad A, Shojaei F, Hesam A, et al. Investigating the mental health and coping strategies of parents with major thalassemic children in Bandar Abbas. *Journal of education and health promotion*. 2015;4.

## Tables

Table 1: Interview guide

| Questions  |
|--|
| What was your child's disease effect on your life?     |
| Please Explain a day of your life with your sick child |
| How do you manage your child's disease?                |
| How to deal with your child's problems?                |

**Table2: demographic characteristics of participants**

| NUMBER OF PARTICIPANTS | SEX    | AGE | LEVEL OF EDUCATION | TYPE OF JOB  | NUMBER OF CHILDREN | OF PARTICIPANT  |
|------------------------|--------|-----|--------------------|--------------|--------------------|-----------------|
| 1                      | female | 28  | diploma            | House holder | 1                  | mother          |
| 2                      | female | 27  | Master's degree    | House holder | 2                  | mother          |
| 3                      | female | 33  | illiterate         | House holder | 1                  | Mother          |
| 4                      | female | 44  | Master's degree    | employed     | 1                  | Mother          |
| 5                      | female | 42  | Primary education  | House holder | 1                  | Mother          |
| 6                      | male   | 33  | Master's degree    | employed     | 1                  | father          |
| 7                      | female | 35  | diploma            | tailor       | 1                  | father          |
| 8                      | female | 32  | Master's degree    | employed     | 1                  | Mother          |
| 9                      | female | 29  | diploma            | Hair dresser | 2                  | Mother          |
| 10                     | female | 34  | Master's degree    | House holder | 1                  | Mother          |
| 11                     | male   | 36  | diploma            | tailor       | 2                  | father          |
| 12                     | male   | 33  | diploma            | unemployed   | 1                  | father          |
| 13                     | female | 39  | illiterate         | House holder | 1                  | mother          |
| 14                     | female | 29  | Master's degree    | employed     | 1                  | Pediatric nurse |
| 15                     | female | 37  | Primary education  | House holder | 1                  | mother          |
| 16                     | female | 32  | Master's degree    | House holder | 1                  | Pediatric nurse |

|           |        |    |                      |                 |   |                    |
|-----------|--------|----|----------------------|-----------------|---|--------------------|
| <b>17</b> | female | 35 | diploma              | employed        | 1 | mother             |
| <b>18</b> | male   | 32 | Primary<br>education | worker          | 2 | father             |
| <b>19</b> | female | 35 | Master's degree      | employed        | 2 | Pediatric<br>nurse |
| <b>20</b> | female | 33 | Associate<br>Degree  | employed        | 3 | mother             |
| <b>21</b> | female | 26 | diploma              | worker          | 2 | mother             |
| <b>22</b> | female | 28 | Primary<br>education | House<br>holder | 1 | mother             |
| <b>23</b> | female | 25 | Master's degree      | employed        | 2 | mother             |