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

Monirsadat nematollahi

Kerman University of Medical Sciences

Roghayeh Mehdi pour Rabori

Kerman University of Medical Sciences

Fatemeh Keshavarz

Kerman University of Medical Sciences

behnaz bagherian (✉ behnazbagherian.bb@gmail.com)

Kerman University of Medical Sciences <https://orcid.org/0000-0003-1809-0537>

Research article

Keywords: epilepsy, grounded theory, coping process, children, parents

Posted Date: May 5th, 2020

DOI: <https://doi.org/10.21203/rs.2.16336/v2>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Version of Record: A version of this preprint was published at Ethiopian Journal of Health Sciences on March 1st, 2021. See the published version at <https://doi.org/10.4314/ejhs.v31i2.16>.

Abstract

Background: parents of children with epilepsy face health-related problems of their children. Coping strategies of parents, major caregivers, affect not only their stresses but also the children's quality of life. This study investigated the coping strategies of parents of children with epilepsy at two educational hospitals affiliated with 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 were collected using qualitative semi-structured interviews and analyzed using the method suggested by Corbin and Strauss version 2008. The Interviews were conducted until thematic saturation was achieved.

Results: the coping process had five phases: disbelief, patience, change to preserve, acceptance of the current situation, and self- empowerment.

In summary, the parents of children with epilepsy had a five-phase coping strategy. The core category was "continued efforts of parents to restore calm."

Conclusion: properly assessing the stresses of parents of children with epilepsy and their coping strategies may help medical staff and social workers provide more targeted support and balance the family function.

Background

Epilepsy is a neurological disorder that is mostly diagnosed in childhood(1).Epilepsy is a life-threatening condition and causes many mortalities and morbidities among children (2). The point prevalence of active epilepsy is 6.38 per 1000 people, while the lifetime prevalence is 7.60 per 1000 people. The prevalence of chronic and epileptic disorders is increasing in the pediatric population due to recent advances in medicine and technology (3). In Iran, 65% of patients with epilepsy are children and teenagers, and 4.2 out of every 1,000 school children have epilepsy (4). The unpredictable and chronic nature of epilepsy can affect the physical and social health of the children and their families. In addition, epilepsy is often associated with psychosocial problems (5).

Besides, The quality of life of people with epilepsy is lower than that of the general population, as well as the quality of life of other patients, such as those with asthma and diabetes (6). Epilepsy leads to problems such as lack of self-esteem, depression, social isolation, and death anxiety because of epileptic seizures (7). Reily (2014) reported that the suicide risk in these patients is two times higher than that of the healthy population (8). Other studies also showed hyperactivity (9), and cognitive disorders (10) in patients with epilepsy. Although many patients with epilepsy have normal IQs, their cognitive functions are weaker than normal population (8). Jones C (2016) found that a child with epilepsy was a crisis for the whole family, and they should be supported to cope with the child's illness. Since the parents consider

themselves responsible for the child's illness, they feel anxious and guilty with a negative impact on the family function (11).

All these problems can affect these parents psychologically (12).

(13). Parents of children with epilepsy are emotionally injured, and their routine life has changed. These parents prefer to stay at home because they are afraid of their child's seizure and the home is a better place for the child in an epileptic episode spend (14). Coping is a process in which an individual attempts to balance his/her life through applying a series of coping strategies in response to a stressful incidence (15). Nurses can help families apply coping strategies appropriately (16). Unfortunately, Iran has limited resources to take care of patients with chronic illnesses. Therefore, it is the family that must take care of the patients (16). Furthermore, nursing home in Iran has very limited services for caring of children with chronic illnesses or disabilities. Providing psychological, financial, and informational support, health care providers can help these families cope with the disease more rapidly (17).

Therefore, it is essential to understand parents' cultural differences in caring needs, experiences and desires, which enable nurses to offer appropriate nursing care and support. In many cases, the personal experiences of the patients and their families can help nurses offer services to minimize their concerns

Previous studies have investigated only one dimension in the life of the parents of children with epilepsy, and according to the review of the literature, no study investigated the coping process of parents of children with epilepsy. In addition, parents' coping process depends on their attitude, level of education, culture, and the number of resources available. A deep understanding of parents' coping process will help the health professionals identify the needs of these children and their families. The current study aimed to explore the coping process in parents of children with epilepsy by using a qualitative grounded theory approach.

Methods

The current study was done using a qualitative approach and grounded theory for identifying the adaptation process of the parents of children with epilepsy. Grounded theory methodology has been an integral part of 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(18).

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 deep understanding of the phenomenon(19).

Research Design and Setting

This study was conducted in Kerman, Iran, from June 2016 to October 2018. Kerman, a city in the southeastern Iran, has cultural diversity and mixed ethnicity. The extent of Kerman province, the dispersion of its population, the high prevalence of epilepsy, and deficiencies in healthcare services caused many problems for the parents of children with epilepsy. In this study, participants included parents of children with epilepsy referring to the specialized neurological wards of two educational hospitals affiliated with Kerman University of Medical Sciences.

Participants and Sampling Method

Purposive sampling was used to select the study participants. 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 1).

The researchers attempted to observe maximum variations in terms of demographic characteristics (numbers of children, education level, and economic status) and type of epilepsy. The researchers also tried to interview with knowledgeable parents whose responses to the study questions could bring about a broad insight. Inclusion criteria included the ability to speak Persian, children aged 1-14 years, diagnosis of child's disease at least one year before the study, and the participants' willingness to participate in this study. Exclusion criterion was cognitive impairment confirmed by a psychiatrist.

Data Collection

Data was collected through face-to-face interviews conducted by a PhD nurse who was a research team member. Team members were three assistant professors and a BSc student of nursing. Both the interviewer and the interviewee agreed upon interview locations and times. The researcher obtained written and verbal consent from each participant.

First, the researcher explained to the participants about the study objectives and benefits. Then, general questions were raised based on the study objectives. Some examples are as follows: how do you manage your sick child? Would you please explain how you take care of your child in a single day? How do you solve your problems? (table2).

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

Data analysis:

Grounded theory method was used in the present study. The transcribed interviews were analyzed using the method proposed by Corbin and Strauss in 2008. Initially, the first author listened to the recorded interviews for several times. Then, the whole conversation was typed verbatim in a Microsoft word document and analyzed using MAXQDA software 10. The transcribed interview was regarded as a unit of analysis. For better understanding, one of the research team members read every finalized document and extracted the semantic units. The semantic units were categorized and summarized based on similarities

and differences, and the semantic codes were extracted. According to the degree of relevance among the semantic codes, they were classified into subcategories with the same subjects. The relevancy of subcategories was assessed, and main concepts were extracted from them. At the end of each step, the research team members extracted and discussed about the core category. The final findings were discussed with the participants in a meeting, and their last remarks were received.

The trustworthiness of the Study

To ensure data credibility, we tried to establish a close relationship with the participants and encourage them to an extensive collaboration. Moreover, we used the ideas and reviews of colleagues, experts. We tried to provide dependable findings through constant revisions by experts and participants as well as external observers. To promote data confirmability, we made a great effort to avoid any personal judgment and experiences. We tried to explain the data as much as possible for maximum transferability of the results

Ethical Considerations

Ethical considerations were addressed before the study. 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 explained to the participants before the interviews, and their verbal agreements were obtained.

Results

Fifteen mothers and five fathers of children with epilepsy, and three nurses were interviewed. The Interviews were conducted twice for three mothers (26 interviews in total). Participants were 28-52 years old (mean 33.5 ± 2.2 years). The children had epilepsy with various intensities (generalized epilepsy, focal epilepsy, and generalized and focal epilepsy), and various treatment regimens (types of drugs). The parents of children with drug-resistant epilepsy and parents of children with other chronic illnesses in addition to epilepsy were excluded from the study.

After analyzing the data, the coping process of parents in caring for a child with epilepsy was described.

In this study, parents of children tried to prepare an excellent situation for them. They were using all available resources. Despite the lack of resources and support, as well as the burden of treatment costs, they resolved these problems by searching and using different strategies.

The coping process had five phases: **disbelief, patience, change to preserve, acceptance of the current condition, and self-empowerment.**

In summary, parents of children with epilepsy have a 5-phase coping strategy. The core category is "continued efforts of parents to restore calm." (table3)

1.Disbelief: the parents of these children did not believe in their disease. This category consisted of three subcategories: denial of the child's illness, escape from reality, looking for the guilty person.

1.1. Denial of the child's illness

Almost none of the parents of these children accepted the condition in the first phase of the disease diagnosis.

Participant No.23 said she had taken her child to several doctors after the diagnosis because she could not accept the reality. Her husband and she had thought that their child had no problem

1.2. Escape from reality

Some of the parents did not follow their sick child treatment. They did not do anything about the definite diagnosis and treatment. They often referred to the hospital when the child's condition was terrible, and the symptoms of the disease worsened.

Therefore, the family were subject to more severe psychological complications, which made the treatment more difficult and complicated.

Participant No.21 believed that some parents did not want to accept their child's disease and reality. They were looking for a new diagnosis, so they changed the doctor.

1.3. Looking for the guilty person: feeling guilty after the definite diagnosis, the parents sought to find the guilty person behind their child's problem.

Participant No. 5 said she had protested against God because of her child's condition. She had begged God to punish her rather than her child.

2. Patience: this category included two subcategories: "**tolerance of care** "and "**endurance of great sufferings** ".Almost all of the participants tried to be patient throughout every stage of their children's illness and treatment; they tried to tolerate the tension inherent in the condition.

2-1.tolerance of care: the parents patiently cared for their sick child at all stages and endured many hardships.

Participant No. 4 said she had breastfed her son slowly without any hastiness because he was not strong enough to suck.

Participant No. 10 said she had not taken her son to the hospital in the planned time because of her bad financial status.

2-2. Endurance of great sufferings: in this study, all the parents mentioned the problems they faced directly or indirectly, and the burdens imposed on them throughout this period.

Participant No. 1 said she had locked herself up at home for at least six months in order not to expose her child to various diseases. She also rarely had gone to the parties to protect her child against diseases.

Participant No. 6 said she had had a difficult situation last year because her son's condition had not been clear. She had had to take him to kindergarten and go to work but it was hard for her son to stay there without his mother.

3. Change to preserve: In this study, change to preserve included two sub-themes: the pressure of the condition imposed on oneself, and change of the routine life.

3-1. the pressure of the condition imposed on oneself: the parents experienced a difficult condition after the child illness. Most study participants had to tolerate some problems because they had no choice.

Participant No. 6 said she had had to take her daughter to the kindergarten for a few days, but her teacher had not accepted to give her medications. Therefore, she had had to wake her up early in the morning and give her medications, and then take her to the kindergarten.

Participant No. 2 said she had had to cook healthy food for her son, and she had prepared fresh food for him.

3-2. Change of the routine life: Because of their child's illness and need for care, the parents tried to adjust their life to spend much time with their child, even if they had to leave their education or their job.

Participant No. 6 said she had been afraid of leaving her daughter alone in the kindergarten. Therefore, she had consulted with her daughter's doctor who wrote a letter to her workplace, and explained her daughter's condition. Then, she had gotten an unpaid leave for three years to take care of her daughter.

Participant No. 5 said she had left her job because of her child's illness.

4. Acceptance of the current situation: in this study, acceptance of the condition consisted of two sub-themes: parental acceptance of the child's condition and child's acceptance of the parents' limitations.

4-1. Parental acceptance of the child's situation: in this stage, the parents accepted their child's illness, inabilities, and limitations after some vicissitudes.

Participant No. 3 said her daughter, husband and she had had to come back home very early after going to a party such as a wedding party because her daughter had gotten very tired late at night. Sometimes, she had preferred to stay at home with her daughter. She had not wanted to impose any pressure or stress on her daughter because her appearance changed when she got upset or angry.

4-2. Child's acceptance of the parents' limitations: some 5-6-year old children can manage themselves. For example, when they have shortness of breath or lack of physical strength and face an epileptic episode, they immediately go to a safe place. They cooperate well with their parents, especially when their mothers instruct them what to do during an epileptic seizure. Participant No 2 said she had not

allowed her son to play outside the house. Instead, she had asked his friends and him to stay at home and play computer games. Her son had realized that running and playing outside the house was not good for him.

5. Self-empowerment: it included self-empowerment of the children to perform self-care activities and use resources and facilities provided by their parents.

5.1. Self-empowerment of the child: children usually become aware of their limitations when they are 5-6 years old, and they can manage themselves. Their mothers mentally prepare them to have more cooperation. They provide necessary information about self-protection..

Participant No. 13 said her son had been aware of the activities that made him feel bad. She had trained and informed him not to do some exercises. She had reminded him the caring tips

Participant No. 14 said his son had been able to search for things related to his disease or problems as well as the answers of questions in the field of his illness.

5.2. Self- empowerment of the parents: parents could empower themselves using resources and facilities available for caring of the child. They tried to provide appropriate care using consultation with professional people (nurses, doctors), innovative methods of care, obtaining information from various sources (books, internet), and using others' experiences.

Participant No.6 said her husband and she had visited a psychologist sometimes to behave their child properly and remove his/her stress.. They had followed the recommendations of the psychologist and carried out all of them].

Discussion

Twenty-three participants (26 interviews) participated in the study. Fifteen subjects were mothers of children with epilepsy, five were fathers, and three were nurses of the pediatric ward. The parents had children with different types of epilepsy and used various types of medications. Disbelief, patience on what happened, change to preserve, acceptance of the current situation, self-empowerment emerged from data analysis.

In this study, parents denied their children's disease and escaped from reality after understanding the first diagnosis of the disease . Helgeson found that parents, especially the mother expected to have a healthy child but suddenly heard about the child's illness (20). Also, Burns and Pop mentioned that the parents' first reaction was to deny the child's disease. Besides, feeling guilty and looking for something to blame is another reaction of parents after a child's disease diagnosis (21, 22). Although these reactions are normal, parents at this stage need psychological support to go through this phase.

Nurses, as crucial members of the health care team, should communicate appropriately to parents at a critical stage (23).

However, parents face lack of resources in Iran after the child's disease diagnosis. 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 the parents and their quality care (24). In this study, some parents adapted faster, and others were not adapted over time. For example, after three or four years of illness, some parents were still asking themselves: "why me?", "why my child?". Many parents said they had tried to be patient against their child's condition. In this study, all the participants were Muslims who believe in patience. They considered religious teachings suggesting that human beings must be patient in the face of problems and that what God wants will happen (26). Parents with stronger religious beliefs were calmer and more 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 praying and going to church are ways of finding peace (27, 28). According to Whaley and Wong, some families believe that every problem is a way to further grace and faith (26). One study investigated Chinese parents' coping strategies for their children awaiting a liver transplant; patient care was represented as an experience by their parents (27).

During the coping process, parents of sick children made necessary changes to their lives to manage child's life. These parents tried to change their routine life to take good care of their children. In addition, nurses should consider these issues when interacting with these mothers.

Financial problems, as well as problems related to physical symptom management, occupational duties, lack of knowledge about care, and problems related to kindergarten and school were the most challenging problems in managing patients with epilepsy in the present study and similar ones (29-33).

Schools and kindergartens should provide conditions for these children to spend a few hours with their peers (in the presence of pediatric nurses and specialists). Therefore, their mothers are mentally relaxed and the children are happy.

The levels of stress, anxiety, and depression are higher among children with chronic diseases than healthy children (34). Therefore, it is necessary to consider their psychosocial and physical health (35). Psychosocial care planning for this group of children will be available with a secure support system and practical with the help of their families. The children's problems can be reduced by training them how to communicate with their peers (34). In this study, some mothers had difficulty in coordinating their working hours with caring for their sick children. In addition, some of them had to leave their work to take care of their child. However, if mothers do part-time work at home, they can tolerate the condition better and their mental strength will increase, and. The improved maternal mood can help them adjust faster to the harsh conditions of childcare. According to some studies, the mother's job leads to greater independence, a sense of self-empowerment, enhanced care and commitment, and a longer life expectancy (35).

After the change to preserve, some parents accepted their condition. They tried to provide practical care by consulting with professionals (nurses, doctors), obtaining information from smart resources (books,

internet), and using others' experiences. In addition, they tried to interact with each other, and learned to take care of one another.

Some cases used specific innovations to improve their child's condition. For example, they asked their children's friends to take care of them at school or purchase brain games because they do not require physical activity.

In most cases, mothers could deal with the conditions created by the disease. For instance, they said they had been mentally better in the surgical or follow-up stages after going through the crisis and facing severe conditions (36).

Knowledgeable nursing staff empower mothers (21), and help them manage the condition. It is essential for mothers living in Iran. The practical nursing interventions (22) and the availability of nurses at all hours, especially when the child feels sick, are essential to adapt faster. Several studies have shown that telenursing systems are significantly useful in creating peace and improving chronic patients and their families mentally. Telenursing systems reduce financial costs, eliminate problems related to long-distance trips, reduce the number of patients' referrals, and improve patients' quality of life (37). However, telenursing systems are not available in Iran.

It is essential to encourage parents to take care of themselves, because they will be able to provide more quality care to their children. 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 (38).

In this study, the parents of children with epilepsy try to adapt themselves to their children's condition by doing particular behaviors. A deep understanding of the coping process can help nurses identify the needs of these children and their parents and enables them to be more aware of the proper management of the disease. Therefore, parents obtain more support, much knowledge and information; reach faster adaptation and, consequently, more accurate care. In addition, a deep understanding of the coping strategies can promote the lives of children and help parents provide 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 based on the grounded theory. The methodology enabled researchers 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 problems. This study found parents' critical role in the care of children with epilepsy, and their multiple challenges. It was found that the parents in this study went through five coping phases and applied coping strategies to minimize familial stress or conflicts. Furthermore, determining parental coping strategies will provide targeted interventions

to improve family function. In addition, the nurses and physicians should understand the path of the coping process. Additionally, the current study helped nurses achieve information about the needs of these children and their parents and solve their problems.

Study limitations

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 results of this study can be applied to families and pediatric nurses in other contexts.

Declarations

Ethics approval and consent to participate.

The Ethics Committee of the Kerman University of Medical Sciences accepted this study with the code of ethics No: 97000448. The researchers informed all the participants about the study objectives. In addition, 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.

Funding

This research was funded by the Research Department at Kerman University of Medical Sciences.

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 collaborated in conducting interviews and transcribing them.

Acknowledgments

The authors would thank all the study participants for their collaboration.

Authors' information

MN, PhD. in Nursing, is an assistant professor in the pediatric nursing department, applied in qualitative research methods. RM, PhD. in Nursing, is presently a lecturer in the medical-surgical department in Razi School of Nursing and Midwifery, Kerman University of medical science, Iran. BB, PhD. in nursing, is an assistant professor in the medical-surgical department in Razi School of Nursing and Midwifery, Iran.

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, Cricchiutti 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. Kozier B, Erb G, Berman A, Snyder SJ. *Fundamentals of nursing concepts and procedures: USA*: Pearson Prentice Hall; 2004.
16. Alaei N, Mohammadi Shahboulaghi F, Khankeh HR, Mohammad Khan Kermanshahi S. Barriers to support for parents of children with cerebral palsy: a qualitative study. *Journal of Qualitative Research in Health Sciences*. 2015;3(4):305-16.
17. 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).
18. Belgrave LL, Seide K. Grounded Theory Methodology: Principles and Practices. *Handbook of Research Methods in Health Social Sciences*. 2018:1-18.
19. Charmaz K. *Constructing grounded theory*: Sage; 2014.
20. 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.
21. 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.
22. 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.
23. Feraco AM, Dussel V, Orellana L, Kang TI, Geyer JR, Rosenberg AR, et al. Tumor Talk and Child Well-Being: Perceptions of "good" and "bad" news among parents of children with advanced cancer. *Journal of pain and symptom management*. 2017;53(5):833-41.
24. Lawoko 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.
25. 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.
26. 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.

27. 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.
28. 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.
29. 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.
30. 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.
31. 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.
32. 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.
33. DeMaso DR, Snell C, editors. Promoting coping in children facing pediatric surgery. *Seminars in pediatric surgery*; 2013: Elsevier.
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.
36. Dadipoor S, Haghighi 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.
37. Ali MM. The religion of Islam: Ahmadiyya Anjuman Ishaat Islam Lahore USA; 2011.
38. 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.

Tables

Table 1: demographic characteristics of participants

number of participants	sex	age	level of education	type of job	number of children	participant
1	female	28	diploma	Householder	1	mother
2	female	27	Master's degree	Householder	2	mother
3	female	33	illiterate	Householder	1	Mother
4	female	44	Master's degree	employed	1	Mother
5	female	42	Primary education	Householder	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	Hairdresser	2	Mother
10	female	34	Master's degree	Householder	1	Mother
11	male	36	diploma	tailor	2	father
12	male	33	diploma	unemployed	1	father
13	female	39	illiterate	Householder	1	mother
14	female	29	Master's degree	employed	1	Pediatric nurse
15	female	37	Primary education	Householder	1	mother
16	female	32	Master's degree	Householder	1	Pediatric nurse
17	female	35	diploma	employed	1	mother
18	male	32	Primary education	worker	2	father
19	female	35	Master's degree	employed	2	Pediatric nurse
20	female	33	Associate Degree	employed	3	mother
21	female	26	diploma	worker	2	mother
22	female	28	Primary education	Householder	1	mother
23	female	25	Master's degree	employed	2	mother

Table 2: 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?

Table 3

Coping process of parents of children with seizure			
Core category	Main category	subcategory	
continued efforts of parents to restore calm	Disbelife	Denial of the child's illness Escape from reality looking for guilt	
	Patience on what happened	tolerant care endure of great suffering	
	Change to preserve	imposing the pressure of the situation on oneself changing the life routine.	
	Acceptance of current situation	acceptance of the child's situation by the parents acceptance of the parents' limitations by the child	
	Self empowerment	Self-empowerment of the child Self-empowerment of the parents	