

# Explaining the Parenting Styles of Epileptic Children: A Content Analysis

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## ABSTRACT

### Objectives

Understanding the parenting practices of parents of children with epilepsy can be a practical guide for care and education planners to prevent mental disorders in these children. This study aimed to explain the parenting practices of parents of children with epilepsy in Shahrekord.

### Materials & Methods

This study is a qualitative study with conventional content analysis. Participants in the study consisted of 20 mothers with epileptic children in Shahrekord, who were included in the study by purposive sampling method with maximum variance in terms of child age, number of family children, and child sex. The data collection method was a semi-structured interview using the interview guide. Data analysis was performed using a conventional content analysis at the same time as data collection. Interviews continued until data saturation was reached.

### Results

The present study revealed five main themes in discipline methods, including over-support / over-protection, forcing to support, rejecting, parental conflict in discipline methods, and using harmful discipline methods.

### Conclusion

In conclusion, the experiences of mothers in the present study show that using inappropriate discipline methods can have adverse effects on the mental-emotional and social health of the child in the future and raise the need to design educational interventions to empower parents of epileptic children in coping with parenting stress effectively.

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## Introduction

Epilepsy is the most common neurological disorder in childhood, and the prevalence is between 3.6 and 4.2 per thousand children in developed countries. Significant medical advances have occurred in the diagnosis and treatment of the disease, but its environmental and socio-social dimensions have been neglected (1). The destructive effects of epilepsy include psychological and social aspects more than the physical dimensions. The burden of illness is not limited to the child but extends to the whole family (2). Living with a child is a significant stress for the whole family. Epilepsy can have direct effects on a child's behaviour and cognitive status. Understanding the child's response to the disease requires awareness of the effects of the disease on the whole family and the community environment around him (3, 4).

These children are at higher risk for behavioural disorders such as inattention and introverted behaviours such as depression and anxiety, in which family environment and parenting practices play a critical role (5, 6). Existing studies have confirmed the high stress on parents of children with epilepsy (3, 7) and its destructive effects on the quality of life of the child and family (8).

Parental stress is a specific form of stress resulting from demands from the parenting role. It is a multidimensional concept consisting of factors that can lead to parental malpractice (4, 3). Fear of the child's death after the first seizure and learning difficulties of the child can create additional stress for the family. Stress in the family can have a devastating effect on parental behaviours and destroy parents' confidence in playing a parenting role (3, 9). Studies have demonstrated that families of epileptic children have more communication and parenting problems (2, 4, 10,

11). Furthermore, studies show that these children are more likely to have behavioural problems in families with poorer parenting performance, and the child's behavioural problems can lead to disorders in the family environment (3, 9, 11).

Despite the fact that parents' coping and management behaviours have a substantial effect on the mental health and quality of life of the child (12, 13, 14, 15), unfortunately, epileptic children are at risk for mental disorders, usually due to parental restrictions. Although some limitations are necessary for epilepsy, many of them are unnecessary and can damage the child's sense of independence and negatively affect their psychological and social adjustment and quality of life (3 and 2). Studies show that parents of epileptic children have at least one epileptic-related restriction on the child. While restrictions do not reduce the risk of seizures, they lead to over-protection by parents. Studies confirmed that parents' anxiety about the possibility of harm puts unnecessary restrictions on the child (16, 2, 17, 18). Such a controlling parenting style can lead to mental disorders in children. Therefore, understanding the parenting practices of epileptic children can provide a practical guide to prevent mental disorders in these children.

Moreover, parenting practices depend on the culture of each community, and these are less known in Iranian culture. A qualitative approach can help to understand this phenomenon better. Therefore, a qualitative study was conducted to explain the parenting practices with epileptic children.

## Material & Methods

A qualitative approach using content analysis was adopted for this study to facilitate a detailed description of the parenting practices of mothers

of epileptic children in 2020. All interviews were conducted by female researchers with Ph.D. in nursing who received formal qualitative research curriculum training. Participants in the study were 20 mothers of epileptic children recruited from a neurology clinic in Isfahan from June to August 2020. They were included in the study by purposeful sampling with the maximum variance of sampling to achieve variation in the children's age, sex, type of epilepsy, the number of siblings and socio-economic class of the family. The sole inclusion criterion was having a child with epilepsy. Data was collected through semi-structured face-to-face interviews with mothers. The interview guide questions were:

- How does the life of an epileptic child differ from other children?
- How has your child's epilepsy affected your relationship with your child?
- How has your child's epilepsy affected your relationship with family members in dealing with your child?
- What parenting methods do you use to raise your epileptic child?

The probing questions were asked to gain a deeper understanding of their experience. The interviews were conducted in a separate room at the Psychiatric Clinic and lasted between 30 and 45 minutes. All expressions of the participants were recorded by the MP3 Recorder with their permission and were transcribed word by word. The participant selection, interviews and data analysis continued until data saturation with 20 interviews, though after 17 interviews, no new concepts emerged. Data analysis was performed with conventional content analysis through five phases (19). In the first phase, interview data was transcribed by researchers and ideas for coding were marked. During the second phase, important

aspects of the data were identified, and codes were extracted. In the third, the initial codes were sorted into potential themes and the relevant codes were collected. The fourth phase involved reading all the collected extracts, considering whether they may reveal a coherent pattern and the validity of the individual themes in relation to the data set. In the final phase, the themes were refined.

#### Ethical Consideration

For confidentiality and autonomy, the purpose of the study, the method of data collection, voluntary participation, and refusal to participate in the study at any time were explained to participants. They were also reassured that their identities would not be reported in the study's research publications. All subjects signed a written consent. The research proposal was accepted by the Ethical Committee of Shahrekord University of Medical Sciences, Shahrekord, Iran (Code= IR.SKUMS.REC.1394.254).

According to Lincoln & Guba (1985) (20), trustworthiness was evaluated by *credibility* (the maximum variation of sampling, peer debriefing and member checking) and *dependability* (concentrating on the research objectives and questions for all participants). The bracketing process helped researchers to assure *confirmability*. Despite the fact that generalizability is not the concern of qualitative research, the maximum variance of sampling was used to enhance the *transferability* of the results.

## Results

Twenty mothers were included in the study. Demographic characteristics showed that the samples were in the age range of 25 to 40 years, had an education level from elementary to diploma and were unemployed. Their epileptic children aged 5 to 14 years old, and the majority

were boys (70%).

The findings revealed five themes relating to mothers' experiences of parenting styles with their epileptic child: over-support/ overprotection, forced-to-support, rejection, parental conflict in parenting styles, and negative disciplinary methods.

#### Theme 1: Protection/ Overprotection

This theme had two domains: over-support and overprotection.

1-1. Over-protection: The experiences of most mothers showed that they are under much stress due to the child's illness and vulnerability. This stress causes them to use overprotective behaviors such as setting limitations or using close parental supervision for sick children to do indoor and outdoor activities, e.g., biking, shopping and playing football, while other siblings had the freedom to participate in such activities.

A mother of a five-year-old girl said:

*I'm taking care of her until evening. She needs watching all the time; she will convulse if she catches a cold, so I have to keep her under surveillance so as not to have the flu or fever. I don't let her go outside ..... I watch her all the time. I never do the same with my healthy children.*

A mother of a six-year-old child stated:

*If he goes everywhere, even the bathroom and delays, I will follow him to check.*

Another mother of a seven-year-old child:

*Well, I was cautious not to let anyone touch her head. I was very sensitive about his head, and everybody told me he was a spoiled child.*

1-2. Over-support: As a result of disease conditions and fear of recurrent seizures, mothers not only couldn't use ordinary parenting methods but also treated considerately and differently and somehow surrendered to the children's wishes.

The mother of an eight-year-old boy said:

*Well, the situation is critical because I am afraid that he will have a seizure. I am more careful; I can't punish him for doing something wrong. I have no choice. I believe that I disciplined my healthy children much better than my epileptic child.*

The mother of a nine-year-old girl said:

*She has become a spoiled brat. I have always told her that if she wasn't sick, I could punish her like the rest of my kids, starve her when she refused the food or force her to study when she did not take the responsibility of doing homework. The doctor told me not to push her. She screams if I force her, it's obvious the pressure is on her brain, so I refuse.*

The mother of a five-year-old girl also said:

*I don't want to upset her. If she becomes sad, she will pull her hair angrily, so we give up and prepare whatever she wants.*

Being the top priority of the mother's life, neglecting the needs of other family members caused the ill child to use his illness as a tool for secondary gain and start blackmailing. Mothers often had to give up and submit to the child's demands, which led to disruptions in sibling relationships.

The mother of a nine-year-old girl acknowledged:

*She is such a spoiled brat that when she wakes up, I have to feed her a morsel of breakfast until midday. My life is messed up. This child takes my whole day with no opportunity to take care of my husband and other children. They say this child is all for you. They are dissatisfied and complain.*

The mother of an eight-year-old boy said in her experiences:

*I have to say nothing often. Nevertheless, his father beat him. His sister is also bad-tempered. They fight each other, but he bullies her, and by the way, the relationship is doomed to failure.*

The mother of a six-year-old epileptic boy with four healthy sisters acknowledged:

*When a baby is sick, you spend more time with him. Especially during childhood, I ignored my husband and other children.*

The mother of a three-year-old boy with a seven-year-old healthy girl also announced:

*I totally ignored my daughter; I mean, I gave her responsibility to my mother because I don't have time for her.*

On the other hand, the experiences of some mothers show that excessive support of the extended family for the sick child and interference in the upbringing of the child prevented the mother from using correct discipline and inevitably surrendering to the child's wishes.

#### Theme 2: Forced-to-protect

The experiences of mothers showed that siblings were always forced to support the sick child. Some siblings sacrificed their rights, and some others were forced by their mothers to do leading to sibling dissatisfaction.

The mother of an eight-year-old boy with a 12-year-old healthy girl said:

*I told my daughter that your brother is sick and younger than you. If he says something, you back off. Don't let anybody bully or abuse him; support him. My daughter bursts into tears and says nothing, then says: I'm crying for Mahdi; why our child must be sick? She has a bad feeling about sacrificing all the time.*

#### Theme 3: Rejection

Mothers repeatedly mentioned that the sick child was rejected by their fathers. Stigma played an important role in fathers' reaction to the epileptic child. They displayed shaming and disgusting feelings of having an epileptic child. Therefore, they were not willing to accompany a sick child and participate in upbringing either indoors or

outdoors.

The mother of a 12-year-old boy with a healthy brother and sister mentioned:

*His father says he makes me disgusted; I hate him. He works in Bandar Abbas; he commutes for two or three months. He only talks to healthy children over the phone. Even refuse to kiss or hug my sick child. My husband prefers to go outside with healthy children. My poor boy understands his father doesn't like him. Not his father nor siblings like him. They'd rather he was never born.*

Based on mothers' experiences, the paternal family usually rejects sick children and supports other children during fights.

The mother of an eight-year-old boy mentioned:

*Once upon a time, my son and my sister-in-law's son were fighting; my mother-in-law said, "don't take this child to our home anymore," and she didn't even permit him to say anything. I interfered and said, "This baby belongs to your family more." She answered, "This is your child, not ours."*

In contrast, in some families, interfering and supporting child-rearing might lead to family conflicts and disputes.

The mother of an eight-year-old boy said:

*His maternal and paternal family love him and support him inappropriately. If they didn't, he probably was a better child. They don't let me discipline him properly. For example, once, he wanted to buy a chicken, but I refused. However, my father said, "don't listen to your mother. Just tell me everything you like. I'll buy it." In this circumstance, I have no choice but appeasement.*

#### Theme 4: Parenting conflict in parenting styles

Some mothers mentioned that fathers blamed mothers for discrimination among children and questioned mothers' discipline methods for sick children. These conflicts lead to severe

parental disputes and somehow other children's dissatisfaction with the mother's upbringing.

The mother of an eight-year-old boy said:

*My husband tells me, "Don't listen to him," but I have to. When my son is under stress, he blushes and becomes aggressive. So I have no choice but to obey him. My husband can't understand him.*

The mother of an eight-year-old boy with a healthy brother said:

*If both of them want me to play with them, I choose Arshia because I feel pity for him. He is sick, and I like him more. If I had some money, I'd rather buy something for Arshia first. His father is objecting all the time, so don't pamper him so much. Why do you prefer him? It doesn't matter if he is sick.*

The mother of an eight-year-old also said:

*Yeah, it differs pretty much, since Mahdi became ill, I'm always arguing with my husband. My child is sensitive and impatient, and my husband doesn't stand him. I'm mother, I understand him much more. I support him, and this battle continues....*

Theme 5: Negative disciplinary methods

The experiences of some mothers showed that the mother was too supportive of the sick child, which concludes irrational expectations of the sick child, resistance to parental demands, and maladaptive behaviour both indoors and outdoors. In turn, some parents had to use negative disciplinary methods such as yelling, physical punishment, rejection, and threatening.

A mother of a six-year-old child said:

*I try to be neutral during children's fights and tell them, "Stop quarrelling," if they ignore me, I show a beating instrument, and everybody escapes...*

Another mother of a seven-year-old epileptic boy stated:

*When he misbehaves, his father beats him, and*

*if he doesn't obey, he puts him in the back of the ally's door. I should return him, I cry. It makes me angry; I curse and shout at him...*

Another mother of a seven-year-old boy stated:

*He is a very stubborn, spoiled and incompatible guy. When he doesn't listen to my word, I'll frighten him by complaining to his father. He backs off and compensates somewhere else....*

## Discussion

The findings of mothers' experiences with parenting styles of epileptic children revealed five themes, including over-support / over-protection, forced-to-protect, rejection, parenting conflicts in parenting styles, and negative disciplinary methods.

One of the themes was over-support/over-protection. Mothers' high levels of stress due to children's sickness and vulnerability lead to using a lot of supportive behaviours, which is consistent with the results of many studies (2,16,17,18). The results of a systematic review by Jones & Reilly (2016) on parental anxiety in childhood epilepsy concluded that mothers' anxiety is associated with lower quality of life and less adaptive behaviours (21). Mullins et al. (2007) also found that the hallmark of chronic illness for both children and parents is the cognitive experience of doubt and uncertainty. The unpredictable nature of many chronic diseases, along with their complexity, makes them challenging to manage and leads to a change in parenting style and how they interact with their children. Excessive controlling behaviours of mothers with strict rules are pretty evident compared to mothers without children with chronic illness (22). However, Akay et al. (2011) found that excessive support and control leads to children becoming more dependent (23). Similarly, Yang et al. (2020) reported restrictions

on school attendance and outdoor activities (24). In a study by Kissani et al. (2020), parents felt that their sick children were not safe alone (25). Important factors determining parental restraint for sick children were female gender and recurrence of seizures. In the present study, girls were more restricted, which was consistent with a study by Austin et al. and Rodenburg et al. (2013) (12,16). Maternal anxiety is a strong predictor of overprotective behaviours in epileptic children (26). However, such behaviours can lead to mental disorders in the child (27, 28,29), and extreme protection makes the child a coward, dependent and inactive (23).

The other theme was *forced-to-protect*. Mothers force their healthy children to provide extreme support to the epileptic child in such a way that they have to give up many rights, including receiving enough attention from their mothers. Nabors et al. (2019) described chronic illness as a family concern, so the family must concentrate on the sick child and pay more attention to them so the family limits the capacity to meet the needs of other children (30).

Alderfer et al. (2010) and Wade et al. (2020) also showed that healthy siblings are in the shadow and deprived of their parent's attention (21, 32). This issue might lead to loneliness, marginalization and neglect of healthy children. In some previous research, siblings understand why parents act differently and feel more responsible (32,34), which is in line with the findings of the present study. Hills (2007) and Jakobson et al. (2020) reported that the family's focus on a child with epilepsy leads to a lack of proper communication and psychological problems between the child and his siblings (35,36).

Another theme was rejection, especially by the father or paternal family.

Some fathers refused to support the epileptic child due to fear of social stigma. In the research of O'Toole et al. (2015), mothers had a more emotional connection with their children and rejection is reported more by fathers (26). On the contrary, Akay et al. (2011) reported a higher level of violence and rejection by mothers (23). Other studies revealed that parental reaction to epileptic children varies from anxiety, stress, rejection and extreme fatigue (21, 24). Social stigma was reported as the worst event of having an epileptic child in some studies (37, 38).

The fourth theme was *parenting conflict in parenting styles*. Fathers usually complained of over-protective and supportive reactions of mothers for sick children and discriminative raising methods among sick and healthy siblings. Soltanifar et al. (2013) mentioned that different parental reactions against sick children could be related to higher levels of stress in mothers versus fathers (39).

Other studies also confirmed that maternal parenting style led to family conflict and disturbance in the social environment of the family (3, 9,11), which is consistent with the result of the present study.

The last theme was applying *negative disciplinary methods*. The current study showed maternal over-protection ingrained in fear of recurrent seizures that led to irrational expectations by sick children, resistance to parental demands and incompatibility with peers. Therefore, parents are forced to use negative disciplinary methods such as yelling, physical punishment, rejection and threats against sick children, which is in line with Knecht et al. (2015) findings. They also showed that parents, especially mothers with children suffering from sudden seizures, have no choice but to surrender to sick child demands in order to

prevent the recurrence of seizures. Ghasempoor et al. (41) reported that epileptic child has severe behavioural, affective and communication problems in comparison with peers (40).

### **In Conclusion**

The findings of the present study showed that parents of epileptic children experience much stress and are continually concerned about sick children, so they apply improper raising methods such as extreme support and over-protection of sick children and somehow negligence of healthy children. These might cause rearing parental conflict and adverse effects on the child's mental, emotional, and social health in the future. Empowering parents by educational interventions to reduce parental stress and applying proper rearing methods to promote the whole family's health is essential.

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### **Author's Contribution**

Simin Tahmasebi: Collaboration in proposal writing. Data collection, Data analysis, collaboration in manuscript writing

Fereshteh Aein: Study design. Proposal writing, collaboration in Data collection, Data analysis, Manuscript writing

### **Conflict of Interest**

The authors declared no conflict of interest.

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