



Family Stigma Associated With Epilepsy: A Qualitative Study

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ABSTRACT

Introduction: Harmful nature of epilepsy can affect the patient and their parent. Stigma, arising from it, affects the patient and their family. To relieve it understanding the experiences of the parent are useful. This study was aimed at understanding the experiences of parent of child with epilepsy in Iran.

Methods: In this interpretative phenomenological study, 10 parents who took care of their child with epilepsy were participated. Data were collected through in-depth semi-structured interviews. After transcription, data were analyzed using Van Manen's method.

Results: Family stigma emerged as a main theme in data analysis with three subthemes including becoming verbally abusive, a dull and heavy shadowed look, and associates interference.

Conclusion: Family stigma is a major challenge for parents of child with epilepsy need to special attention by health system. Nurses, as a big part of the system, can play an important role to manage this problem.

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Introduction

Epilepsy is a common neurological disorder¹ that can be associated with symptoms such as convulsions and loss of consciousness.² The prevalence of this disease is 0.52% in Europe, 0.68% in the US, 1.5% in developing countries³ and 1.8% in Iran which is more common in female.⁴ In approximately 50% of cases, the onset of disease symptom is before age.⁵

Epilepsy leads to psychological problems such as mental disorders, mood disorders, suicide and social isolation, feelings of shame and guilt, low self-esteem, anxiety, pessimism about life, and stigma.⁶ Many problems that the child faced with impact on the family and they may experience the low self-esteem than peers, psychological and learning problems.⁷

Their family also may have many problems such as anxiety, depression, feelings of guilt, anger, hopelessness and shame.⁸ Moreover, they have sleep disorder, high level of stress and low quality of life. Therefore, uncertainty about child and family future has negative

effects on family functioning⁹ which all of the problems could impact on their job.¹⁰ Parfene and colleagues reported that parents of a child with epilepsy received fewer workplace rewards such as promotion and greater workplace penalties such as job termination than other counterparts.¹⁰

Social acceptance of the child and coping with epilepsy remain as a concern for parents¹¹ as the family try to hide epilepsy because of discrimination in social issue like taking job and getting marriage. Based on a study in Iran only 28% of participants was agree with marrying with a person who has a epilepsy.¹²

There are approximately 600000 patients with epilepsy living in Iran and so the patients and their families are engaged in the process and treatment and the consequences of the disease.¹³ Over 70 million people live in Iran and most of them are Muslim. About feature of the culture that can be mentioned altruistic and strong family ties are very important,¹⁴ so a commitment to sensitive care for an ill family member is valuable especially if the ill member

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is a child. Iranian people are quite affectionate and have a close relationship with their child; in addition, Islam also often mentions the importance of parent-child responsibilities, so parents are committed to provide all aspects of care in any situation for their child, especially when the child is sick.¹⁵ In this context, parent could be affected by other people reaction to the child's sickness. Consequently, all aspects of a family's social life and health care providers¹⁶ could be negatively affected by stigma.^{14,16} Forsgren and colleagues (2013) compared experience of stigma by Iranian and Sweden person with epilepsy and suggested the Iranian patients reported greater internalized stigma than the Swedish patients, but no study about parents' experiences of child with epilepsy was found.¹⁷

Few studies about the experiences of parents of child with epilepsy have been conducted. Also, no study was found about this subject in Iran. Because of the harmful nature of epilepsy such as isolation from close relatives and community and multicultural differences in Iran and the lack of knowledge related to the nature of caring of child with epilepsy in Iranian context, and personal experiences of the researcher (first author) lead to design this study.

Therefore, this study aimed to understand the lived experiences of parents of child with epilepsy in Iran. Providing this information may will be effective for the health system and the staff employed by it, especially for nurses as the largest part of the health system in Iran.

Materials and methods

This study is based on the philosophical perspective of the naturalistic and the phenomenological approach. Van Manen's method of doing phenomenological study was used in this study. Van Manen described interpretative phenomenological method as a combination of interpretation and describing, and believes that they are not separate.¹⁸ He introduced a methodological theme as a practical approach to the interpretative phenomenology. In these studies, the phenomena experienced by individuals has been identified through their descriptions

about the inside world. Since Van Manen focused on the life world, the lived experience of the parents was the center of attention in our study.

This study was done in Tehran Iran in 2014. Ethical approval was obtained from the Ethics Committee of the Research Deputy in the Tehran University of Medical Sciences with the permission number 2505/d/93. After receiving permission the researcher referred to Imam Khomeini Hospital and Children's Medical Center, two referral governmental hospitals that eligible parents could be found there. The parents who had only one grandmal epileptic child with 1 to 18 years old, and at least diagnosis of epilepsy by neurologists were selected to the study. The parents should be living with the child and bear responsibility for taking care of the child and not be separated and have epilepsy themselves, be literate, and physically and mentally health one to participate in the study and be able to communicate verbally. Before data collection, the aim of the study was explained to the participants, and for interviewing and recording oral and written informed consent was obtained from them. They were assured that participating or not would not influence their child caring and treatment. They were also allowed to quit at any stage of the study. The researcher provided them a phone number so they could ask questions or provide additional data if needed.

In this study, purposive sampling was used. Moreover, to achieve rich data maximum variation sampling strategy was used. Finally a total of 10 parents participated (6 females and 4 males), aged between 20 to 42 years (the mean age was 34.1 years). A total of 14 interviews were conducted (6 participants were interviewed once and 4 twice). Two participants because of doctor visit were interviewed again and 2 others accompanied their child to paraclinic and the interview was interrupted, so it was done again (Table 1).

Data were collected through in-depth semi-structured, face-to-face interviews with individuals in a quiet room. Place, date and duration of interviews managed based on each participant will. The length of each session

ranged from 35 to 100 minutes. When the analysis showed no new themes the sampling was ended. Each interview started with the questions: Please tell me about your life when you realized that your child has epilepsy, what is living with a child with epilepsy like? How you experienced living with a child with epilepsy? And other probing questions were asked such as: Can you give an example? Can you explain more? The interviewees were asked for more clarification of the responses. All interviews were recorded on digital audiotape in a MP3 file format, and then files were transcribed to the plain text verbatim.

Data analysis was done according to Van Manen's method. At the first step after thoughtful perception of a parent of an epileptic child we formulated phenomenological question. Researcher experience on parent of epileptic child was written. At the second step, literature review was done. After understanding the whole, a selective approach was used to isolate the thematic statements. Researcher endured prolonged engagement and conducted the in-depth interviews. At the third step, within 48 hours each interview was transcribed into plain text verbatim. Listening to audio and reading transcriptions were repeated several times to avoid making mistake and immersing thematic analysis was performed with data to get at the essential meaning of the experience.

Holistic and selective approach was used for exploring themes. At first, the whole of each transcript was read and a brief was written. In selective approach, each transcript was read line by line and statements that reflect family of children with epilepsy stigma were identified. At the fourth step, trying to provide a good description of the phenomenon as Van Manen stated, theme and phenomenological text was written. At the fifth step, to maintain a correct way, original questions were referred to and in the last step; we repeatedly referred to the whole and part of the context. In the report of the findings, the numerical values were used for each participant instead of their actual name to maintain anonymity.

Validation Criteria in Van Manen methodology. Van Manen 1990 noted a term

"validating circle inquiry" in "phenomenological nod" which indicates a good phenomenological description. For this, the date was referred to 4 participants by random to confirm the descriptions.¹⁸

According to Van Manen methodology, researcher avoided the using of non-phenomenological research method such as member check.¹⁹ Also, data analysis was only done on the accounts and transcribes and perceptions, opinions, beliefs, views of researchers were not concerned. Review of the records and writing a short transcription were performed several times, data immersion, data analysis in collaboration with other colleagues, reflections on writing, in order not to deviate from the main issue turning to the research question at any point of the study, and attempt to generate a rich description of the phenomenon was done. Researchers analyzed till received at deep, rich, relative and abstract themes, and adhere to Van Manen methodology principles at all stage of this study.

Results

Family stigma emerged as a main theme for this study. Because of others treatment, family of children with epilepsy conceal their child's disease. The family prefers to hide epilepsy diagnosis from others till they would be less responsive and ridiculed. These behaviors include sarcastic words, meaningful looks and interventional recommendation. As a whole, there were three subthemes for family stigma as becoming verbally abusive, a dull and heavy shadowed look, and associates interference.

- **Becoming verbally abusive**

One of the factors that lead to parent stigma of children with epilepsy was the verbal abuse by others. Sometimes for sympathy statement made by them, intentionally or not, angered the parent and had led them to not being willing to talk about their child's disease and concealing it from those around them and, and if their child has a hospital stay they give another reason. The participants discussed as below:

"For example, they tell us, don't be worried, it will be okay, but from the tone of their voice you understand that your child's problem is so huge, so what they say is not polite"(p4).

"When I took him to school for first registration, after I explained my child has epilepsy, the first man did not know what the problem is and another man who was older said it is better for him to be out of school"(p9).

A mother with 7-year old daughter said:

"they say "oh, do not worry she will marry", I do not know why when we mentioned her disease, people think about her future and her marriage while I think it's not a problem and many people have epilepsy, are they not married? "(p7).

- A dull and heavy shadowed look

Other items that lead to the family stigma were associates with others nonverbal treatment and staying away from the sick child:

"They looked us as if our child has AIDS, our child is sick and we are not responsible for it. I do not know why people look at me like that, it's so irritating that I want to die. It is so good that others are unaware of my child's disease" (p5).

A father of a 9-year old boy said:

"When my mother realized it she visit our less than before, sometimes she made an excuse such as

illness or going to another place, but then we realized something was wrong. She didn't kiss my son after she learned about his illness, can you believe it? All mothers are happy to have a grandson but her..." (p6).

- Associates interference

Sometimes associates try to impose their opinion on the children regardless of the parents' opinion or want the parents to behave in accordance with their wishes. Due to the close family ties, in this manner it is seen as interference in the affairs of life by some.

One mother of a child with epilepsy said:

"Everyone does and says whatever they want; they think that because our child is sick we don't understand anything. One told us "you shouldn't have another child because it may be sick too" this is so irritating so we don't discuss it"(p1).

"My mother and mother-in-law want us to conceal it because they believe she will be labeled, I don't like their comments and have repeatedly told them that, we understand the situation and we don't need their advice or comments, as this situation happened after the birth of my daughter "(p3).

Table 1. Participant's characteristics

Participant	Age	Job	Marriage	Education	Home	Child disease duration	Child gender	Interview room
P ₁ , Mother	40	House keeper	Married	Diploma	Tehran	11	Female	Children's Medical Center
P ₂ , Mother	28	Seller	Divorced	Academic	Tehran	7.0	Female	Children's Medical Center
P ₃ , Father	36	Staff	Married	Diploma	Tehran	4.0	Male	College
P ₄ , Mother	32	House keeper	Married	Under diploma	Abadan	1.5	Male	Children's Medical Center
P ₅ , Mother	33	House keeper	Married	Diploma	Tehran	5.5	Male	Children's Medical Center
P ₆ , Father	42	Staff	Married	Academic	Tehran	7.0	Male	Clinic
P ₇ , Mother	20	Student	Married	Academic	Tehran	1.5	Male	Clinic
P ₈ , Mother	38	House keeper	Married	Under diploma	Hamadan	4.5	Female	Children's Medical Center
P ₉ , Father	37	Staff	Married	Academic	Tehran	1.0	Female	Children's Medical Center
P ₁₀ , Father	35	Staff	Married	Diploma	Tehran	6.5	Female	School of nursing

Discussion

In the study, family stigma emerged as a major theme that refers to courtesy stigma that Goffman mentioned.²⁰ The type of stigma was less mentioned in the literature, but stigma in patient suffering from leprosy, AIDS, and mental illness was mentioned.^{21,22} Among these, stigma in patient with epilepsy was

assessed many times but in their family it was less studied, although in Goffman's opinion patient families are at risk.²⁰ In the study, stigma emerged as a major theme. Li et al., reported that 89% of people with epilepsy and 76% of their families in China have been stigmatized.²³ Navab et al., also, regarding the stigma among caregivers of patients with Alzheimer's disease writes, caregivers of the

patient were stigmatized, she reported because of feeling of shame due to the unusual behaviors and speech they prefer less attendance in communities and they were isolated,¹⁴ which is consistent with the results of our work. Bogart et al., suggested all family members of people with AIDS were stigmatized, 100% of their mothers and 88% of fathers and 52% of children.²⁴ Verbal abuse is one of the subthemes, sometimes the Iranians use sarcastic words to send their message. According to these findings, it seems that parents of children with epilepsy are targeted. Considering to the experience of these parents of children with epilepsy, they deprived of a great deal of social activities such as marriage and employment. Based on the cultural and religious context marriage is very important and considerable attention is paid to it, and it is believed that a person who does not marry will not enjoy a good life later.

Having the same belief about a child with epilepsy, people make sarcastic comments to their parents that bother them. Fear of such attitude toward their children leads to concealing the child's sickness. Aronu & Iloeje suggested the parents of children with epilepsy are ridiculed and embarrassed due to having a child with epilepsy and their seizure,²⁵ which is a kind of verbal abuse; this was also mentioned by our study participants. These parents were discriminated because others talk with them in a different way and discrimination is a part of the stigma. Elafros et al., also reported discrimination against mothers of children with epilepsy.²⁶ Verbal abuse is not solely associated with non-verbal gestures and actions that can be transferred to the parents of these patients, and even reduces the relationship with the family. This is described as "a dull and heavy shadowed look" by parent that distempers them. This is also a kind of discrimination. As Goffman has pointed out, others negative attitudes lead to discrimination.²⁰ As well as my result, Parfene et al., suggested the same findings. They suggested employers of those who have a child with epilepsy discriminate between them and others who do not have a child with

epilepsy. So they are given fewer workplace rewards, for example, opportunity for promotion, and they are given greater workplace penalties such as job termination, than other employees. They believe such parents are more likely to be absent from work and they are stranger than others. From their view, these people are not the best candidates for work compared with others and their work may be affected by the negative consequences of the patient care. They also noted that both mothers and fathers are equally exposed to stigma in the workplace.¹⁰

Associates interference was the third subtheme that emerged. There are still extended families in Iran with close relationships, despite the spread of nuclear families these relationships still remain. The Iranians are also affectionate and willing to help others, especially close relatives or associates. So they sometimes comment on the issue to help, without considering the situation. According to our participant experience, such comments are sometimes assumed as interference in family life and they cause anger. Because our people are very sensitive about interference this may be lead to separation.²⁷ Barikani et al., suggested the relative interference as one of the main causes of divorce in Qazvin province, Iran.²⁷ The same as others, parents of children with epilepsy are therefore very sensitive to this type of treatment around them and their marital life can be threatened by associates' interference. It seems that this behavior leads to isolation and detachment from social relationships.

Conclusion

Family stigma is a major challenge for parents of child with epilepsy need to special attention by health system. Nurses, as a big part of the system, can play an important role to manage this problem.

To manage this problem, the health system should develop supportive strategies such as enhanced familiarity to epilepsy and parent's problems. In this line, information should be given by mass media such as TV, radio,

newspaper, and magazine in term of epilepsy. Also nurses must be educated and sensitive of stigma, as a missing subject in nursing curriculum, and educate the parent about their stigma and the consequences and how they can relieve it. Nurses can set up consultations and educate the parents to participate in it, talking about stigmatization. Community health nurses should visit relatives and associates to encourage them to participate in relieving this problem if it is necessary.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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