



The experiences of Iranian patients with epilepsy from their disease: A content analysis

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ABSTRACT

This qualitative study investigated experiences of patients with epilepsy in Iran regarding stigma. Twenty-two participants were chosen by purposive sampling method. After getting informed consent, we conducted and recorded interviews and then transcribed them verbatim. After that, all the researchers read the texts thoroughly, and the data were analyzed using conventional content analysis method. Seven categories emerged from the analysis including need for support, defense mechanisms, superstitious beliefs, negative feelings, negative reactions of others, imposed deprivations, and spirituality. These results will increase healthcare professionals' knowledge about the problems of Iranian patients with epilepsy and improve the design of healthcare models that can promote successful coping strategies for them.

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1. Introduction

Epilepsy is a neurological condition that occurs with equal frequency across geographic, social, and racial boundaries. It has been estimated that there are at least 50 million people worldwide who suffer from epilepsy [1], making it one of the most prevalent neurological disorders. Although epilepsy can affect people of all ages, it seems to affect the younger people (i.e., persons younger than 60) more frequently [2].

In developing countries, there are approximately 35 million patients with epilepsy, and approximately 85% of them are not being treated for the disease [1]. A national study in Iran found that the prevalence rate of epilepsy in rural and urban populations was approximately 1.8% and common in women, the unemployed, and the people with high education [3].

The term epilepsy is derived from a Greek word meaning "conquered by an external force". The condition's history includes 4000 years of ignorance, superstitions, and shame labels followed by 100 years of social stigmatization. This situation has led to incorrect

presumptions about the basic causes of the disease and has resulted in injurious social labels causing patients' suffering [4]. So, patients with epilepsy suffer from discrimination and morbidity associated with seizures [5].

Studies in South Korea, England, and Japan have investigated how epilepsy caused various negative effects in patients' lives. The results showed that the unemployment rate of people with epilepsy in Korea was approximately 31% (i.e., five times greater than that of the rest of the population). In England, 21% of employers indicated that employing patients with epilepsy is a significant problem. In Japan, a study of 278 patients with epilepsy indicated that 68% were married and seven individuals (two males, five females) were separated because of epilepsy [4,6].

Negative consequences of stigma like social withdrawal, embarrassment and shame, and the failure to marry and occupation additionally impair the quality of life in most patients with epilepsy [7]. Stigma in epilepsy is more frequent in developing countries [8], but there are no published reports investigating whether Iranian (northwest) patients with epilepsy have these types of problems because of the disease. Considering the high prevalence of epilepsy, psychiatric disorders, suicide attempts [4], and the poor quality of life of Iranian patients [9], it seemed valuable and critical to investigate the experiences of patients with epilepsy within the Iranian cultural context. Thus, we conducted a qualitative study as it was the most suitable method for determining the

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extent of how Iranian patients are negatively affected by epilepsy [10]. So, we investigated the experiences of patients with epilepsy regarding stigma.

2. Methods

This study was conducted using conventional content analysis method to explore the experiences of patients with epilepsy in an outpatient clinic in an educational hospital affiliated to Ardabil University of Medical Sciences, Iran.

Before data collection, the main interviewer [S.A] met the managers of the medical center and informed them about the aim and method of the study to get their permission for conducting the interviews.

2.1. Data collection and interviews

Data collection was carried out using semistructured interviews which were conducted over a 6-month period in 2015 (from February to October). Authors collaboratively developed the interview guide from the list of the topics that found in the literature. However, to be inductive, the literature was set aside at the beginning of data gathering.

After getting informed consent, two patients were interviewed and reviewed by the first researcher to ensure the adequacy of data. Face-to-face semistructured interviews were done in local (Turkish) and national (Persian) language in an agreed place (often in a private room in hospital), and lasted for a maximum of 1 h. At first interview, a general question “tell me about your experiences of having epilepsy”, or “can you tell me about any problems you have faced while having epilepsy?”, was asked, and to seek further information, interviews were continued by questions like “Why should this be so?”, “What do you mean about that?” or phrases such as “please explain this further”. Besides, some notes were taken during the interviews for further clarification of the data. The taped interviews were transcribed verbatim and analyzed simultaneously. The data gathering continued until data saturation, when no newer information could be obtained. Data saturation occurred when data analysis did not result a code or new category, and in this study, a saturation point was reached when no new data or category emerged after the interview with the 18th participant.

2.2. Participants

Twenty-two participants were recruited by purposive sampling method, and to ensure maximum variation, the participants were sufficiently diverse in terms of age, gender, education level, employment, and epilepsy histories. Purposive sampling method was applied by instructing the neurologist working in the hospital's outpatient epilepsy clinic, and diagnoses of epilepsy were confirmed by a fully-trained neurologist (G.F) who reviewed medical files and electroencephalographic and imaging reports.

To recruit our research participants, we contacted adult patients (≥ 20 and ≤ 60 years) with a diagnosis of epilepsy according to the criteria of the International League Against Epilepsy (ILAE) who attended the outpatient neurology clinics of the referred hospitals affiliated to Ardabil University of Medical Sciences, if they met the following criteria:

1. Having generalized tonic-clonic epilepsy (although diagnosis could have occurred at any time since birth).
2. Having controlled epilepsy and no significant intellectual disabilities, learning difficulties, and/or developmental delay.
3. Willing and able to participate in the study and share information regarding their disease.

Exclusion criteria included epilepsy surgery within six months ago, diagnosis of additional psychogenic nonepileptic seizures, and severe comorbidity that would have justified hospitalization (e.g., suicide).

2.3. Analysis

After data collection, conventional content analysis method was used to analyze the data [11] in which two main researchers [P.M & M.K] independently reviewed the transcribed interviews and manually coded, determined, and categorized them. P.M is a specialist in mental health, and M.K is a professional in qualitative research. The two lists generated by each researcher were used as a stimulus for discussion. The analysis was conducted by a system of open coding to develop the first categories. Interviews were organized into units, and then they were summarized and changed into codes. The primary codes were categorized based on their differences and similarities, and then secondary codes were developed. At this level, the secondary codes were discussed and reviewed to achieve major categories which were classified as third level codes [10].

2.4. Quality assurance

The trustworthiness of the research was assured by including maximum variety of subjects and getting data saturation. Interviews were also recorded and transcribed verbatim to avoid any data miss. Also, member checking was used to confirm correct description of some interviews. As mentioned before, coding and analysis were done by the two researchers to ensure the consistency and get similar results. Besides, we strengthened the study using peer-checking.

2.5. Ethical considerations

The Research Ethics Committee of Ardabil University of Medical Sciences approved the research proposal (IR.ARUMS.REC.1394.72). In addition to providing information about the objectives of the research to the participants, they were assured that their information will remain confidential and their identities would be protected and not published in research reports. All participants signed informed consent prior to their inclusion in the study, and they were told that the study was voluntary and they could decline to participate or withdraw from the study at any time.

3. Results

The mean age of the participants was 27 years. Demographic characteristics of participants are shown in Table 1.

In this study, seven major categories were found: need for support, defense mechanisms, superstitious beliefs, negative feelings, negative reactions of others, imposed deprivations, and spirituality (Table 2).

Table 1
Demographic characteristics of 22 study participants.

Variable	M (SD) n (%)
Age (years)	27.08 (6.59)
Age of seizure onset (years)	5.5 (2.3)
Gender	
Female	10 (45.5%)
Male	12 (54.5%)
Marital status	
Married	2 (9%)
Single	19 (86.5%)
Divorced	1 (4.5%)
Living arrangement	
With spouse	2 (9%)
Alone	5 (22.72%)
With other family	15 (68.18%)
Type of seizure	
Tonic-clonic	14 (63.63%)
Myoclonic	5 (22.73%)
Absence	3 (13.64%)

Table 2
The main concepts of experiences of patients with epilepsy.

Themes	Subthemes
Need for support	Good reaction from relatives Support of important people
Defense mechanisms	Hiding the disease because of shame Denial
Superstitious beliefs	Gradual adaptation with imposed deprivations Believe to punish the patient by God because of his or her guilt Going to the writer of amulets and benedictions
Negative reactions of others	Not to accept the patient Tease Offer to separation Labeling
Negative feelings	Fearing of (disease, rejection, marriage, driving, being alone, future) Low self-confidence Suffering
Spirituality	Being hopeful Religious beliefs
Imposed deprivations	Deprivation of marriage Unemployment Stopping education

3.1. Need for support

All of the participants who had been supported by their parents and close relatives experienced good reactions from others, continued their education, and reported more positive mood. Spousal and physician support was effective in promoting disease acceptance. Teacher and employer support, a positive reaction from neighbors, and learning about the disease were effective in increasing the patients' quality of life.

However, patients who were deprived of these supports experienced many problems such as stress, low self-confidence, depression, and lower education level. All of the patients shared a need for support from others and desired to have normal interactions with other people. They also desired an increase in public knowledge, a reduction in superstitious beliefs about epilepsy, and fewer presentations of unreasonable fear of epilepsy in the public media. One of the patients said, "Why isn't there a chapter about epilepsy in the science books in schools? Education should begin during childhood in the schools because school is the first place that forms children's minds. Television is also important."

3.2. Defense mechanisms

Almost all of the patients tried to hide their disease in different places and times (because of fear of being labeled and the resultant deprivation), emigrate to places where no one knew them, and going back to home to gain family support (in cases that the patient was studying in another city).

For example, one patient declared, "my mother and father tried to hide my disease a lot; it is not good for a girl to have any defects."

3.3. Superstitious beliefs

The belief that unpleasant clinical manifestations of the disease caused vulgar disfigurements was common and fueled by social culture and public knowledge. Common superstitious beliefs included that the patient was damned and should go to faith healers or the illness was a punishment from God for the patient's guilt.

As one patient said, "They (parents) took me to the doctor and writer of amulets a lot, but it was not effective. None of them (medications or amulets) were effective".

3.4. Negative feelings

Unpleasant feelings, including shame, guilt, internal regret, and fear, were the most experienced among patients. They were frightened of being alone, not being accepted by others, marriage (i.e., consequent separation), the effect of the disease on their lives, and their children having the illness. These emotions resulted in depression, isolation, pessimism, and low self-confidence. Our research also revealed that the patients experienced unpleasant and hurt feelings, rejection from the public, imposed deprivations, a sense of shame in being different from others, and a sense of regret resulting from the deprivation.

"During childhood at school, when we were going to play football, my classmates said to the teacher, we don't want him to play with us, and I cried and was angry. At parties, everyone looks at me in ways suggesting I should not be angry and not have a seizure and I don't like this. So, I don't like to go to parties".

3.5. Negative reactions of others

Some people around the patients avoided doing group work with them or did not accept them in the community. Negative reactions to the patients included teasing, despising, taunting that the disease is transmissible, calling them liars, labeling them (e.g., "fairies"), habitually swooning, insisting on separation after marriage, and unsupportive teachers who feared being attacked by the patient. All of these had a deep effect on the patients' social communication. For example, a 27-year-old female patient said, "My father cannot control himself at all and considers me guilty". Most of the participants affirmed teasing the patients with labels like fairy or liar had deep psychological effects on them and their communication.

A patient remarked, "At first I hide my disease from my roommates; when I entered the university, they called me 'fairy'".

3.6. Spirituality

Some patients believed that their illness improved as a result of praying, going to holy shrines, and asking for help from Imams. In addition, after relapsing, praying and worship were effective for their mood and helped them adapt to stressful conditions. A 22-year-old woman said, "My illness has been given by God and everyone who teases me is guilty. God has considered it good for me".

Another patient also said, "I don't fear having a seizure in public; maybe it is a divine exam for me and people should not tease me in this regard."

3.7. Imposed deprivations

Several patients experienced deprivation from marriage, not having a permanent job, unemployment, job termination, and educational discontinuation.

A patient said, "Some years ago, I was going to marry, but something happened and I decided not to marry. It was better for me. I didn't know that spouses can cancel the marriage because of this disease. One time, I heard from my friends that my illness can cause dissolution of the marriage. At that time, I loved a boy, and he was in love with me, but I decided to break off the relationship without saying the reason and never marry anyone".

4. Discussion

To our knowledge, this is the first qualitative study to describe the experience of stigma in Iranian (northwest) patients with epilepsy. The findings share similarities with the extant literature in terms of the patients' methods of coping with epilepsy and other chronic diseases.

Epilepsy is a disorder with psychological outcomes; and compared with other people, these patients experience increased stress and depression and decreased self-confidence. Stigmatization often results from the unpredictable nature of the seizures and has many effects on social interactions, public health, employment, and overall quality of life. Our patients adapt to their problems and imposed deprivation by trying to be like normal citizens and hiding their disease. These results are consistent with other studies, which report 31% to 68% of patients with epilepsy perceive stigma [12–16].

On the other hand, the need for support was common in every interview. These supports were effective in improving the quality of life, and patients who were deprived of these supports had many problems such as stress, low self-confidence, depression, and poor education level. Lower perception of stigma has been found in individuals with more social and family support in other studies [17–19].

As well, other studies stated that any kind of stigma leads to low levels of revelation of the disorder and lower levels of social support of participants. Actually, unrevealing may lessen the incidence of enacted stigma, but, by not discussing their disease, patients may bind their opportunity to get social support. This limited social network can affect health outcomes and lead to a low quality of life and well-being [20].

The important point in this study was that most patients wanted the public media to make people more aware about epilepsy and several participants attributed the stigma of epilepsy to the lack of knowledge about the disorder and fingered that community education is the best way to eliminate the problem. Not understanding the disorder leads to the perception of epilepsy as dramatic, which is a basis to the development of stigma [7]. Unfortunately, public education regarding epilepsy is limited, and only 5% of adolescents reported having education on the disorder [21]. Educational productions, media campaigns, and informative negotiations have been reported as effective means in improving public view about epilepsy, and public education campaigns on epilepsy and psychosocial interventions for people with epilepsy positively impact their quality of life [22].

In addition, support groups who address stigma, coping, and self-efficacy have been shown to decrease internalized stigma and improve psychosocial functioning [23,24]. In study conducted by de Boer et al., it was suggested that quality of life and public knowledge about epilepsy could be increased by presenting information in school handbooks [13].

de Souza and Salgado argue that shame and negative feelings form because of varied and complicated factors and the intensity depends on social and cultural backgrounds. Thus, the most effective methods of reducing the shame associated with epilepsy should be based on ways to remove these main causes. In addition, there should be attention to the patients' social problems with a personal approach to remove the internal causes of shame [4].

The uniqueness of this study lies in the emphasis on the spirituality. Some patients believed that their quality of life was improved by praying and going to holy shrines because it was effective on their spirit and their ability to adapt to stressful conditions. This strategy helped them to revise their views about the disease and as a result, helped them to overcome their problems. The patients considered the disease as their “destiny” and “God’s test”; as a result, they surrendered themselves to their fate. More than 80% of the studies have shown that religion has a significant role in improving well-being; especially, the literature indicates that religious beliefs and rituals lessen feelings of a lack of control on diseases [25]. Hosseini et al. declared this theme as “confronting the disease using a religious approach” [26]. Religious adaptation refers to how religious beliefs and insights affect one’s reactions in stressful times that stretch beyond the limits of normal adaptation [27]. Considering that most of the Iranian population (approximately 98%) are Muslim and that a religious culture is dominant, religious beliefs are expected to play an important role in daily life, especially in critical conditions [28,29]. Thus, one way to help

patients is to encourage them to adopt an approach that uses their religious beliefs.

4.1. Limitations

The sample size affected the scope of the findings in this study. Future research using a larger sample will enrich our understanding of the needs and contributions of patients with epilepsy. In addition, the lack of data on the patients' level of functioning and frequency of seizures does not allow us to verify fully the weight of the patients' condition on experienced stigma. Also, this study was limited to patients attending a tertiary center in Iran (northwest), and generalization of the results to populations outside the region and who are not get care may be affected.

5. Conclusion

We found that patients with epilepsy suffer from various negative social and psychological effects of the disease. A good understanding of the effect of epilepsy stigma on the patients will help healthcare team to better tailor support systems to this population. Also, the focus of this study was the northwest of Iran; this can be quite advantageous since gathering and analyzing in-depth, qualitative data from a specific area give healthcare providers in that area information about how to care better for the patients in their region.

Conflict of interest

All authors declare that they do not have conflict of interest.

Informed consent

Informed consent was obtained from all individual participants included in the study.

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