

Explaining the Process of Adaptation to the Disease in Patients with Epilepsy: A Qualitative Study

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Abstract

Background: The concept of adaptation has gained central importance in research on chronic diseases. However, this process is not clear in adult epileptic patients. This study aimed to explain the process of adaptation to disease in patients with epilepsy.

Methods: This study was conducted using the grounded theory approach from December 2018 to January 2020 in Isfahan, Iran. Data were collected by semi-structured interviews with 18 patients with epilepsy. Participants were selected by purposeful or theoretical sampling method. Data collection was performed by the first author through conducting semi-structured interviews. Data analysis was performed by Strauss and Corbin's (1998) method.

Results: Four main categories with ten sub-themes were obtained from the data analysis. The main themes include "Perceived disorder," "Scrimmage with the disease," "Moving towards adaptation," and "Balancing life." The Core category achieved was "Trying to balance life."

Conclusion: Based on the results, the process of adapting to epilepsy has four stages: "Perceived disorder," "Scrimmage with the disease," "Moving towards adaptation," and "Balancing life." The health providers' awareness of these stages can provide a framework that can be used to help epilepsy patients achieve positive adaptation. Achievement of adaptation can help epileptic patients control the disease and improve their quality of life.

Keywords: Epilepsy, Seizure, Adaptation, Adjustment, Qualitative research, Grounded theory

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Introduction

Epilepsy is a disorder of the central nervous system identified by seizures (1,2). Having two or more seizures at least 24 hours apart that do not have a known cause is considered to be epilepsy (3). In 2020, the prevalence of epilepsy in the world (0.5–3%) was more than 50 million people, and its incidence was estimated to be 4–7 patients per 10000 people. Epilepsy affects 1% of the population at the age of 20 and 3% of the population at the age of 75, and its prevalence is slightly higher in men than in women. In 2018, there were more than 1 300 000 (1.7%) people suffering from epilepsy in Iran (4).

The unpredictable and chronic nature of epilepsy can affect the physical and social health of patients and their families. Epilepsy is also often accompanied by psychosocial problems (5). People with epilepsy are at potential risk of sudden death if they do not control their seizures. Moreover, their social activities, such as marriage, employment, and education, are severely limited. Uncontrolled seizures cause physical injuries

such as head trauma, fractures, and burns (6) but also lead to psychosocial problems such as depression, anxiety disorders, and decreased quality of life (7). Chronic disease affects individuals' social, physical, and psychological domains (8,9), so adaptation to disease in patients requires changes in psychological, social, and physical aspects of life (10).

Adaptation is a mental process in which a person endures and copes with the various needs and pressures of illness, and this process is formed in the social context (11). Research has shown a significant difference between individuals in adaptation to a multidimensional structure (12).

The adaptation process is influenced by various factors, such as illness perception, social support, and personality traits (13,14). Researchers suggest that psychosocial adaptation to chronic illness may be a one-dimensional spectrum from incompatibility to successful adaptation (15).

Studies show that adaptation to epilepsy affects life



in various ways, including fewer seizures, returning to work, increasing safety, appropriate reaction to the disease, and improved lifestyle, ultimately increasing the quality of life (16). In a qualitative study about the self-management of epileptic patients in Iran, three main themes were presented, including "Perception of threat to self-identify," "Effort to preserve self-identity," and "Burnout" (17). In another study, Bagherian et al stated how parents of children with epilepsy adapt to their child's disease. They explained five phases: Disbelief, patience on what happened, change to preserve, acceptance of the current situation, and self-empowerment (5). In addition, some studies have addressed the relationship between emotional intelligence and coping strategies (16) or self-compassion and adjustment to epilepsy in epileptic patients (18).

Despite some limited studies in this field, no studies have been found regarding the adaptation process in Iranian adult patients with epilepsy. Furthermore, patients' adaptation process is influenced by their attitude, level of education, culture, and the availability of resources.

Health professionals need a deep understanding of the adaptation process of patients to meet the needs of these patients and their families. This study utilized a qualitative approach and grounded theory to identify the process of patients' adaptation to epilepsy. Grounded theory is a structured, yet flexible methodology. This methodology is appropriate when little is known about a phenomenon; the aim being to produce or construct an explanatory theory that uncovers a process inherent to the substantive area of inquiry (19).

Methods

This qualitative study was conducted at Isfahan Epilepsy Association from December 2018 to January 2020. The data were analyzed using Strauss and Corbin's approach (1998) to grounded theory (20). Strauss and Corbin define grounded theory as a theory derived from data systematically gathered and analyzed through the research process (19). The study population was epileptic patients who were members of the Isfahan Epilepsy Association. Sampling was performed purposefully at the beginning of the study, and theoretical sampling continued with maximum variation in terms of participants' age, gender, duration of disease, and financial status. The inclusion criteria were age over 18, ability to speak and understand the Persian language, no known psychological problems, and agreement to participate in the study.

We referred to the Isfahan Epilepsy Association and explained the objectives of the research to the center's officials. First, we identified the eligible subjects according to the association's patient records. Then we created a list of people with epilepsy who seemed to be able to provide us with helpful information. Afterward,

we phoned the patients on the list and invited them to participate in the study. If they agreed, we asked them to determine the preferred time and place for the interview. The first participant had epilepsy for seven years before recruitment to the study. He had a school education and seemed to provide us with helpful information. He preferred to be interviewed in an interview room located at the Epilepsy Association.

The first author performed data collection by conducting semi-structured interviews. The interviews mainly started with the following questions: "Please tell me about your illness," "How do you cope with your illness?", "How do you manage your life in the face of illness?", and follow-up questions based on patients' answers. Besides these questions, we used probing questions such as "Can you explain more about this?" and "Can you clarify this?". Data collection was finished when all categories were saturated. In total, 18 individual interviews were done.

Data analysis started immediately after the first interview and continued simultaneously with data collection. Accordingly, the research team listened to the interviews several times and made a verbatim transcript. After that, interview transcripts were read multiple times to obtain a general and precise understanding of the data. Then, the statements containing important points about the adaptation process were identified as the units of analysis. After that, the meaning units were condensed, abstracted, and coded. For example, the meaning unit of "The number of seizures has decreased since I take medication and eat a proper diet" was condensed to "Decrease of seizures through medication and diet" and labeled with the code "Decrease of seizure." Subsequently, the codes were compared with each other, and those with similar content were grouped into the same categories. Codes formed the primary categories, and the primary categories created the sub-categories, and the sub-categories generated the main categories. Coding and categorization continued until the main theme of the study was generated.

In establishing trustworthiness, Lincoln and Guba created stringent criteria in qualitative research: credibility, dependability, confirmability, and transferability (21). For the credibility of the findings, we selected the best statements as the meaning units, prolonged our engagement with the participants and the data, and performed concurrent data collection and analysis (22). The dependability of the data was established by having peers participate in the analysis process. In addition, peers conducted a step-by-step repetition of the study to identify similarities in results or enhance findings. The transferability of the findings was established through sampling with maximum variation and providing thick descriptions of participants' characteristics and experiences.

Results

Ten males and eight females aged 19–61 years with a disease duration of 2–23 years participated in this study (Table 1).

Results of the study showed that participants' main concerns are disruption of their life balance due to frequent seizures and side effects of medications. Some raised other issues, such as their disease-related restrictions regarding education, marriage, and choosing a job. The participants stated that they underwent different adaptation phases after being diagnosed with the disease. Several contextual factors are critical to successfully transitioning through the stages of adaptation. These factors include social, economic, and emotional support. We will discuss some strategies used by patients to achieve positive outcomes. Patient statements indicate that effective mechanisms for facilitating positive adaptation have resulted in a reduction in seizure frequency. As a result of the patient's efforts to adapt to their newly acquired environment, life balance is achieved.

The main theme of "Trying to balance life" was abstracted during the data analysis process. The main categories of this main theme were "Perceived disorder," "Scrimmage with disease," "Moving towards adaptation," and "Balancing life." A summary of the study results is presented in Table 2.

Perceived disorder

Perceived disorder is one of the first and most important stages of adaptation based on the participants' experiences. The initial reaction of patients when being diagnosed with the disease is classified into three modes:

lack of insight, denial, and surrendering to the disease.

Lack of insight

At the time of diagnosis, some patients and their families had no insight into the disease, and they attributed the problem only to external factors such as the doctor's incorrect diagnosis, family problems, and air pollution. One of the participants, a 41-year-old man, said:

"All these symptoms I have are related to air pollution. It is not clear what is in this air that on a sunny day, I became like this." (P3; 41-year-old male)

In this regard, another participant said:

"When they said I'd had a seizure, I didn't believe it. I thought the doctor was wrong. I did many tests..." (P 8; 31-year-old female)

Denial

Some patients denied their illness after being diagnosed and could not accept that they had epilepsy. Some others who were aware of the nature of the disease rejected being epileptic. In this regard, a young male participant said:

"When I went to the doctor and he told me I had epilepsy, I said to myself, 'No, this is not true, I am young, and no one in our family has this disease. I know I'm healthy'" (P12; 25-year-old male)

Surrendering to the will of God

Eventually, the patients accepted their disease after various tests and over time. Some of them considered their illness to be the will of God and decided to submit to his will. One middle-aged female stated in this regard:

"It is difficult for me to talk about my illness, but I have

Table 1. Clinical and demographic characteristics of participants

Identification code	Age (y)	Gender	Education	Marital status	Employment	Duration of illness (y)
1	42	Man	Primary	Married	Employed	7
2	36	Female	Primary	Married	Homemaker	6
3	41	Man	Associate Degree	Married	Employed	11
4	27	Female	Bachelor	Married	Homemaker	3
5	53	Man	Primary	Married	Retired	23
6	21	Female	High School Diploma	Single	Homemaker	21
7	40	Female	Primary	Single	Homemaker	19
8	31	Female	Primary	Married	Homemaker	3
9	33	Female	Bachelor	Married	Employed	15
10	38	Female	Primary	Married	Homemaker	2
11	44	Man	Primary	Married	Unemployed	18
12	25	Man	Bachelor	Single	Employed	5
13	23	Man	Diploma	Single	Unemployed	4
14	56	Female	Primary	Married	Homemakers	17
15	61	Man	Primary	Married	Retired	11
16	30	Man	Bachelor	Single	Employed	8
17	35	Man	Associate Degree	Married	Employed	13
18	19	Man	Primary	Single	Unemployed	19

Table 2. Categories and sub-categories of adaptation to the disease

Category	Sub-category	Open code
Perceived disorder	Lack of insight	The disbelief of the disease Misdiagnosis
	Denial	Avoid treatment Secrecy
	Surrender to the will of God	Acceptance of the disease God's will
Scrimmage with disease	Recognize limitations	Harmfulness of food with cold nature Annoying noise Inability to do heavy physical activity
	Occurrence of psychological symptoms	Feeling depressed Anger Feeling guilty
Moving towards adaptation	Adaptation strategies	Gaining awareness about the disease Request for social support
	Effective adaptation	Follow-up treatment Taking medication
	Incompatibility	Fatigue of illness Abandoning treatment
Balancing life	Back to life again	Continuing education Deciding to get married
	Increase life expectancy	Planning for the future Self-management of disease

accepted it. My illness was God's will." (P14; 56-year-old female)

Scrimmage with disease

The second category extracted from the interviews with the participants was called "Scrimmage with disease." The two sub-categories related to it include "Recognizing the limitations" and "Occurrence of psychological symptoms."

Recognizing the limitations

At this stage, the patient will learn the limitations epilepsy creates. These limitations, which are gradually discovered by patients over time and through experience, are the situations that cause seizures. For example, they believe they should not engage in strenuous physical activities or prolonged exposure to crowded and noisy environments.

"Because of disease, I cannot do things such as mountaineering, doing heavy exercise, or staying up late ..." (P13; 23-year-old male)

"I can't tolerate loud noises or intense light, so I can't go to celebrations." (P10; 38-year-old female)

Occurrence of psychological symptoms

Among the problems that patients experienced after the disease was the onset of psychological symptoms, such as depression, anxiety, stigma, embarrassment, and feeling of inadequacy, due to news of the diagnosis and the nature of the disease.

"After hearing about the diagnosis, I lost my temper with the slightest problem for a long time ... I was depressed".

(P17; 35-year-old male)

"I feel that my life is aimless, and I don't enjoy anything in my life. Nothing in life is important to me anymore" (P2; 36-year-old female)

Moving towards adaptation

This category was the result of three sub-categories "Adaptation strategies", "Effective adaptation", and "Incompatibility."

Adaptation strategies

Applying unique situational strategies helps people deal with difficult situations positively. Participants used strategies based on gender characteristics to adapt, such as praying, appealing to the Imams, controlling stressful situations, engaging in side activities, and other effective factors.

"I try to keep busy, read books, go out with my colleagues, and cook new dishes ..." (P7; 40-year-old female)

A 56-year-old woman states in this regard: *"Faith in God is very important. As long as I am in the mosque praying, I am calm..."* (P14; 56-year-old female)

Effective adaptation

Some people will achieve positive and effective adaptation by using adaptation strategies. They viewed the disease as a companion and believed it would not be a problem for them as long as they controlled it.

"I, indeed, have some limitations, but my disease is not incurable ... It is controlled with medicine, and I have no problem." (P4; 27-year-old female)

Incompatibility

Some participants said that despite the use of adaptation mechanisms, they have not yet been able to adapt to their disease. Frequent seizures, side effects of medications, financial problems, and lack of adequate support from family or community are some of the reasons for this incompatibility. A 36-year-old woman expresses her feelings as follows:

"I think my life has been destroyed. I dislike everything. I get angry very quickly. Everyone knows me as a sick person. I always have to take medicine... I am unhappy with this situation." (P2; 36-year-old female)

Balancing life

The other category of this study was "Balancing life". This category includes "Back to life again," and "Increase of life expectancy."

Back to life again

A decrease in the number of seizures leads to a normal life. Some participants stated that they were able to continue their everyday lives as before without seizures disrupting their daily activities. As one participant who

had not experienced seizures for a long time stated:

"I have not had a seizure for some time. I take my medicine on time. Everything is under control, and I am comfortable. This is how life goes on." (P9; 33-year-old female)

Increases in life expectancy

Some participants mentioned plans for the future for themselves and their families, which shows increased life expectancy. Continuing education, marriage, and parenthood are some things the participants mentioned in this regard.

"I feel like after a stressful period in my life I have returned to normal conditions. I would like to get married and start a new life ..." (P16; 30-year-old male)

"I feel much better now; I go to work; sometimes I go out with my friends. I am planning to continue my education ..." (P9-F-33 years old)

Discussion

The study's results showed that the participants went through different stages from the time of diagnosis to complete adaptation. In our study, these stages included: "Perceived disorder," "Scrimmage with the disease," "Moving towards adaptation," and "Balancing life." The first category is "Perceived disorder." After the diagnosis of the disease, the patient's reactions are different. Some accept it immediately, some deny it, and some may not have any insight into the disease. However, the patient must accept the disease to reach the next stages of adaptation. Benbadis confirms the different reactions of epileptic patients at the time of diagnosis (23). This reaction was presented under three sub-categories of lack of insight, denial, and surrender to the disease in the present study. In the study of Bagherian et al, which was conducted on the coping of parents of children with epilepsy, the parents' reaction after the diagnosis of their child's illness was "Denial of the child's illness," "Escape from reality," and "Looking for guilt" (5). In the qualitative study by Hosseini et al, in the first stage of adaptation, the theme of "Perception of threat to self-identity" was revealed. This means that the epileptic patient feels that their self-identity is threatened and must try to preserve it. "Different view of epilepsy" and "Being a burden" were the sub-categories of this theme (17).

Patients can identify their limitations in the next stage, understand the factors that influence their disease, and learn how to change their lifestyle regarding diet, activity, sleep, and rest. For example, they discovered that food with a cold nature was more likely to cause seizures. Participants reported feelings such as depression, anger, despair, indifference, and guilt at this stage, and scrimmage with the disease happens. Yennadiou and Wolverson reported that three overarching themes emerged from analyzing the experience of epilepsy in ten

older people: "The power of epilepsy," "They say you can live a normal life but you can't," and "Attempts to adjust and cope" (24). Similarly, Kılınc et al reported that three superordinate themes were identified from thirty-nine adults with epilepsy in the UK. Firstly, "Negotiating the space between health and illness," secondly, "Tensions in adopting a biomedical perspective," and thirdly, "The need for broader support" (25). Although these studies have not explained the process of adapting in patients with epilepsy, in the experiences of people with epilepsy, the need for more support and efforts to adapt to the disease have been mentioned, which is in line with our results. Ghafari et al have identified seven themes in adapting patients with multiple sclerosis: "Religiosity," "Information seeking," "Support," "Hope-raising," "Emotional reactions," "Concealing the disease," "Fighting the disease," and "Disability" (26). Epilepsy, like MS, is a chronic disease, and the results are comparable.

The third category is "The move toward adaptation." The chronic nature of epilepsy necessitates adaptation in patients. Some will achieve effective adaptation, and others will not. Selecting appropriate adaptation strategies is very effective. Deegbe et al introduced positive coping strategies in PWE, including problem-solving, belief in God, social support, and lifestyle changes (27), which align with the current study's results. In another study, adaptation strategies are divided into the three categories of cognitive, behavioral, and emotional skills used in managing stressful situations (16). The results of studies conducted in Iran show that patients use an emotion-oriented approach to adapt to the disease rather than a problem-oriented one. These strategies include using religious inclinations, seeking support, fighting the disease, defending oneself against the disease, hiding the disease, and expressing emotions (28,29). Some strategies to help patients adapt to the disease include focusing on the disease, following up on medication, getting enough sleep, eating healthy nutrition, reducing stress, receiving social support, and changing lifestyles. However, the negative strategies in adaptation are fears of seizures and concealment of the diagnosis. The effectiveness of these adaptation strategies will lead to various health outcomes, including reducing the severity and frequency of seizures, the possibility of adapting to work situations, and performing daily activities without fear of seizures (27).

The fourth category is "Balancing life." The participants' statements in this study showed that patients with effective adaptation can manage their disease and reduce the number of seizures (30), so adaptation to the disease would improve quality of life. Also, disease control is possible by self-management; by returning to everyday life, a balance in life is created. Some studies in this area have stated that epilepsy self-management would increase patient's competence, quality of life, control of disease, and self-efficacy (31-33).

It is important to note that one limitation of this study is the psychological condition of the patients, which was beyond the researcher's control. It is also important to mention that the results of qualitative studies are not very generalizable.

Conclusion

The study results indicate four stages of adaptation to epilepsy that can be used as a clinical guideline to facilitate adaptation to the disease in epileptic patients, enhance healthcare providers' knowledge about the process of adaptation, and design care models that will promote successful strategies to combat epilepsy. Epileptic patients may be at any adaptation stage, depending on their background conditions. Thus, health providers can develop strategies to help them adapt positively. Adapting to the disease can help epileptic patients better control and improve their quality of life. This study provides a knowledge base on adapting to epilepsy, which needs further testing and development.

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Competing Interests

We have no conflicts of interest to disclose.

Ethical Approval

The Ethics Committee of Ahvaz Jundishapur University of Medical Sciences approved this study (IR.AJUMS.REC.1396.622). We entered the study setting after obtaining permission from the setting's administrators. The purpose of the study was explained to the participants, and their written and verbal consent was obtained. They were assured that the information they provided would remain confidential.

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