

Determining the disease management process for epileptic patients: A qualitative study

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ABSTRACT

Background: Epilepsy exposes patients to many physical, social, and emotional challenges. Thus, it seems to portray a complex picture and needs holistic care. Medical treatment and psychosocial part of epilepsy remain central to managing and improving the patient's quality of life through team efforts. Some studies have shown the dimensions of self-management, but its management process of epilepsy patients, especially in Iran, is not clear. This study aimed to determine the disease management process in patients with epilepsy in Iran.

Materials and Methods: This qualitative approach and grounded theory study was conducted from January 2009 to February 2012 in Isfahan city (Iran). Thirty-two participants were recruited by the goal-oriented, and snowball sample selection and theoretical sampling methods. After conducting a total of 43 in-depth interviews with the participants, the researchers reached data saturation. Data were analyzed using Strauss and Corbin method.

Results: With a focus on disease management process, researchers found three main themes and seven sub-themes as a psychosocial process (PSP). The main themes were: perception of threat to self-identity, effort to preserve self-identity, and burn out. The psychosocial aspect of the disease generated one main variable "the perception of identity loss" and one central variable "searching for self-identity."

Conclusions: Participants attributed threat to self-identity and burn out to the way their disease was managed requiring efforts to preserve their identity. Recommendations consist of support programs and strategies to improve the public perception of epilepsy in Iran, help patients accept their condition and preserve self-identity, and most importantly, enhance medical management of epilepsy.

Key words: Epilepsy, grounded theory, Iran, management, qualitative research, seizure

INTRODUCTION

Patients with epilepsy, a chronic neurological disease with seizure episodes, are exposed to a wide range of psychosocial experiences far more disabling than the disease itself.^[1] The psychosocial aspects of epilepsy include a high rate of psychotic reactions, mood disorders, and suicide.^[2] Epileptic patients experience a sense of shame, guilt, low self-esteem, anxiety, depression, and pessimism.^[3]

Behavioral and psychosocial adjustments are made by patients with epilepsy to control seizures and attain a higher quality of life. Behavioral adjustments include medication adherence, adequate sleep, good nutrition, and stress reduction.^[4]

Chronic disease management could be a patient-directed effort with supervision and lifestyle changes. Epileptic patients confront daily challenges to maintain a productive life and increase life expectancy.^[5] Behavioral changes and lifestyle modification are the coping methods that help manage difficulties associated with epilepsy and are essential for seizure control.^[6] There is basic emphasis on adjustment with the seizures, suitable reaction of individuals

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Submitted: 03-Aug-14; Accepted: 07-Jul-15

Access this article online	
Quick Response Code:	Website: www.ijnmrjournal.net
	DOI: 10.4103/1735-9066.174748

and family to the disease, employment rehabilitation, creating safety and improving life style.^[5] Patients with epilepsy can adjust themselves with their disease to avoid seizures by changing their lifestyle, and this can be achieved by getting good sleep and controlling their stressful way of life, paying special attention to their regimens, and by medication compliance. All of these contribute to increase their quality of life, and information plays a crucial role here.^[4,7]

Although some studies have offered strategies for medical and self-management of various chronic diseases, the paucity of research on the management process of epilepsy as a life-altering disease seems evident. Fraser *et al.* analyzed the concept of chronic self-management and offered three approaches: (1) Treatment management, (2) role management, and (3) emotional management.^[8] Sattoe *et al.*^[9] and Shegog *et al.*^[10] found three primary behavioral domains for self-management: (1) Treatment management, (2) seizure management, and (3) lifestyle management.

The experiences of individuals diagnosed with epilepsy and their reactions and interactions with family, community, healthcare providers, and with each other are essential in management of the disease. Therefore, management of epilepsy is possible only through a study on the patients who have experienced the disease and those who have had interactions with them.^[11]

Numerous research studies on self-management of epilepsy have been published,^[9,10] but the researchers did not find any comprehensive study about the psychosocial process (PSP) of epilepsy management in the literature, especially in Iran with a different culture, religion, and social structure, and how patients struggle to manage their disease. So, the researchers aimed to determine the disease management process for epileptic patients and highlight the importance of managing epilepsy in a social structure such as Iran, by introducing the concept of management, supervision of patients by self, the medical staff, and families, while promoting patient autonomy and independence. The researchers' team consists of experienced doctors who are faculty members in psychology health nursing, community health nursing, and other related expertise, especially in qualitative research. They have published many qualitative articles in different fields such as epilepsy and other subjects. Also, they have held a number of workshops in qualitative research.

MATERIALS AND METHODS

This qualitative study was based on Strauss and Corbin's grounded theory and was conducted from January 2009 to

February 2012 in Isfahan city (Iran). This method achieves the research objectives in a social dynamic where epilepsy and human behaviors could be best described.^[12,13] According to literature, patients with epilepsy have many problems in psychosocial behavior due to the nature of epilepsy and the community's view about seizure. So, the grounded theory is the best method because it explains human behavior and captures social process, human experience, human interaction, and social concerns in social context.^[13]

The study participants were the individuals diagnosed with epilepsy. They were selected through a purposeful and snowball sampling process. Then theoretical sampling was used for generating theory when primary codes emerged in comparative analysis and was continued throughout the study. Grounded theory was used during sampling, data collection, and analysis, and 32 samples participated in this research, including 22 patients with epilepsy, 5 healthcare personnel, 4 family members of the patients, and 1 epilepsy association member. Of the total number of participants, 18 were females and 14 were males in the age range of 18–61 years. The inclusion criteria for 22 patients with epilepsy were age above 18 years with diagnosis confirmed by a specialist and at different acuity levels of the disease. Participants were mentally competent and at least 2–24 years post-diagnosis. Sample selection occurred at the local epilepsy association, physicians' offices (neurologist's and psychiatrist's), and at the medical and psychiatry hospital wards. Five medical and nursing staffs were recruited with 5–20 years of working experience in the neurology ward of Kashani Hospital in Isfahan. There were four family members of patients with epilepsy, including father, sister, and mothers. Researchers discontinued data collection once saturation was reached (no new data emerged), common themes and categories were formed, and central variables for grounded theory were identified.

The main data collection method in this study was a semi-structured in-depth interview. After getting acquainted with each participant, the study subjects were asked to sign a written informed consent. Researchers obtained verbal permission to audio tape the interviews and assured all participants of maintaining strict privacy and confidentiality, as voluntary participation was emphasized. Each interview lasted 30–150 min and some of the participants had between one and three interviews for a total of 43 sessions.

After obtaining demographic data, researchers began the interviews with one general question, i.e. "Please tell me about your disease" or "How did you learn about your disease?" or "Tell me how your disease has affected your life and your behaviors." According to the participants' answers, the next set of questions were formed using who, what,

where, when, why, and how to further explain personal perspectives. The interviews were recorded on an mp3 player. In addition to semi-structured interviews, field notes, observations, and memos were used as supplemental data.

Corbin and Strauss guide was used to analyze data through simultaneous comparative method as data were being continuously collected.^[14] The three stages of open coding, axial coding, and selective coding were applied. In the open coding stage and at the end of the first interview, the transcribed content of every session was reviewed word-by-word and line-by-line as the obtained data were fragmented into significant parts. In this stage, the main sentences were extracted and a code was allocated to each sentence according to its concept. Then the encoded data were compared to cluster similar codes based on their specifications and dimensions. When the primary classifications of the codes were performed, a number of key concepts and categories were identified. In the open coding stage, a large number of open codes were assigned through reduction and verification. Only 191 codes and nine primary categories were considered. The same data analysis process was applied for field notes, memos, and participants' memory collections.

For the axial coding stage, the initial codes and primary categories from the open coding stage were compared with each other and those with similar concepts were merged into one. The correlated categories were also placed around a common axis, which ultimately formed an abstract concept through an induction and deduction process. In this stage, classifications were condensed to create a phenomenon with a background in which the phenomenon occurred.

In the selective coding stage, data were compared using techniques such as writing the main story, diagrams, conceptual models, and review memos. Researcher was able to conceptualize the main psychosocial problem, as the central category among other categories was identified. In this stage, the basic effort was focused on the correlation of concepts with each other, within categories, and with the central category. The final phase was to form a research hypothesis on the management of epilepsy based on the hidden variables in the main story. At last, the researchers retrieved support from the published literature to develop a theory.

The obtained data were assessed for credibility, dependability, conformability, and transferability to assure accuracy and rigor for a qualitative approach. Credibility was ensured through simultaneous comparative analysis as the participants reviewed data for clarity and precision while code extraction matched their lived experiences. Two experienced external reviewers examined our data controlling for unbiased reflections and data collection by

interviews, observations, field notes, diaries, memo, and diagrams. Participant profiles showed variability in age, sex, socioeconomic status (SES), culture, disease acuity, and the history of disease onset. Credibility of our findings was enhanced by examining various related theories. Conformability and dependability were established by external observers (experienced faculty members). After slight revision, an agreement was obtained between researchers regarding the matter. The experiences among the participants in the study were found to be similar to those individuals who were not enrolled.

This study was an excerpt of an approved doctoral dissertation thesis with the proposal number of 387061, conducted at the Isfahan University of Medical Sciences (IUM). All participants signed an informed consent prior to participating in the study. They participated voluntarily and were reassured of the confidentiality of the data and anonymity.

Ethical considerations

All participants signed an informed consent prior to participating in the study. They participated voluntarily and were reassured of the confidentiality of the data and anonymity.

RESULTS

A theory emerged from this grounded theory research. The “perception of identity loss” was identified as the main psychosocial problem and “search for self-identity” emerged as the main and central variable. In this theory, perception of identity loss with epilepsy is a trigger for the management process of epilepsy in patients and their families. Therefore, they take efforts to preserve self-identity by some strategies, but the main problem remains and they have a sense of burn out. Despite having the feeling of burn out, they search for self-identity. In this research, patients pass PSP as given in Table 1.

Perception of threat to self-identity

This phase identified the sense of self-abasement and having doubts with a different glance at epilepsy. The

Table 1: Psychosocial process of disease management for patients with epilepsy

Themes	Sub-themes
Perception of threat to self-identity	Different glance at epilepsy Being a burden
Efforts to preserve self-identity	Concealment Cooperative self-management Struggle for equilibrium
Burn out	Ineffective disease management Helplessness with endless tensions

identity disruption was attributed to the nature of disease, misunderstanding the disease, and insufficient or lack of support. Iranians often believe a public display of seizure is an act or cry for help as a beggar.

Participant #3 (22-year-old girl): *When a person is having convulsion or fit on the street, people think he is acting or asking for money like a beggar. I saw someone on the street having a fit and most people would pass by and treat him as a beggar and throw money at him while he was weeping hard.*

One of the participants believed that epilepsy was caused by evil spirits.

Participant #15 (29-year-old man): *I think that metaphysical factors have a role in this case because 60–70% of diseases which involve the brain include the evil spirits.*

The following patient shares feeling about the effect of epilepsy on the personal and family prestige:

Participant #14 (40-year-old man): *I do not admit having epilepsy because I feel ashamed.*

The father of an epileptic patient endorsed a sense of disgrace associated with epilepsy.

Participant #17 (62-year-old father): *Public misperceptions are hurtful to our family name and prestige.*

Patients experience unemployment, fear job security, experience economical and educational setbacks, and feel being a burden or a social parasite.

Participant #9 (24-year-old man): *Epilepsy is a major barrier to finding and getting a job for most of us. As the saying goes, “you can’t always get what you want.” We lose many things because of unemployment. We are dependent on our families, and cannot become independent. This is a big problem.*

Participant #16 (26-year-old woman): *I left school because of being sick. I had a teacher who was very strict. During an examination, I had a seizure and he thought it was a lie. He took my hand and threw me out, disallowing me to finish the test session. On follow-up, even the school superintendent had a very bad behavior.*

Efforts to preserve self-identity

The perception of threat to identity emerged at the beginning of the first stage and evolved into the next stage where efforts had to be made to manage the disease and preserve self-identity. Participants identified uncontrollable fits as a direct risk to their identity and recognized that only

adequate medical management could help them avoid fits and live a normal life. Participants experienced and went through these steps to protect their identity.

Concealment

Participants intentionally concealed their diagnosis of epilepsy from the public.

Participant #30 (23-year-old woman): *Sometimes I hide myself when having a fit so nobody would find out, but in some occasions, I am exposed before reaching my hiding place, and go into convulsion.*

With regard to the mean stares and negative attitudes in the community, one participant called epilepsy “a hidden disease” to express the level of secrecy and sensitivity.

Participant #20 (21-year-old girl): *Epilepsy should be called as a hidden disease. I do not have as much problem with my disease as the community portrays.*

Cooperative self-management

Participants realized that hiding their disease was not always effective, because its discovery seemed inevitable. The sub-category of cooperative self-management emerged when patients decided to cooperate and conquer their disease by accepting family support and medical advice. This strategy was essential to maintain self-identity and participants agreed that they have to consistently comply with the medical management of the disease in order to control seizure episodes. Although self-management seems to be a simple strategy to overcome seizures, participants were also aware that accomplishing such task needed self-directed determination and accepting responsibility with support from the family members and the medical team.

To gain control over personal life and contain the seizure episodes, participants had to adhere to the drug treatment. All of the participants stated the main reason for taking their medication was to avoid public embarrassment and preserve self-identity, as given below:

Participant #31 (28-year-old woman): *Being afraid of somebody seeing me having seizure, I take the medication.*

Epileptic patients need motivation, supervision, and family support. However, excessive support could have an adverse effect by reducing patients’ motivation and stop them from accepting personal responsibility for their daily treatment. This especially happens in families which are dominant and overprotective with constant reminders.

Participant #10 (50-year-old man): *Since I got married, I have taken my medications on time. When I forget, my wife*

quickly reminds me. For example, if I am sleeping and she finds out I have not taken my medication, she will wake me up even if it is three in the morning. She calls me or comes to remind me that I have not taken my medicines. She calls my cell phone to ask where I am or if I have taken my medicine.

By self-management and lifestyle modifications, patients have been largely able to reduce the incidence of seizures and overcome their fears. Participants and their families have learned to avoid what provokes seizure, such as certain edibles recognized as cold-natured foods, anger and tension, intellectual activities and studying, missing medication doses according to the time table, sleep disruption, sports and intense physical activities.

Participant #15 (29-year-old man): *Tea, vegetables, pickles, juice, salad, soup, fish, yogurt, cucumber, shrimp, lemon, lettuce, spinach, garlic, and egg-plants are poisons for me. When I eat food with warm nature like dates, I have fewer seizures. I try not to eat things with cold nature. When I eat fish, I also eat 2–3 dates for balance.*

It is important to mention that majority of Iranians believe in cold- and warm-natured food products and they practice food balance to maintain good health. In this study, the family members carefully observed which food was appropriate to eat or avoid for seizure reduction.

Participant #6 (patient's 54-year-old mother): *I pay close attention to what he eats and would not give him any cold-natured foods. I cook warm-natured foods and balance his nutrition.*

Strategies to reduce tension and increase calm and tranquillity were implemented. Participants sought tranquillity when angered or while weeping.

Participant #12 (27-year-old woman): *I quickly get angry and in my opinion, seizures can be reduced by having inner calm and happiness.*

Families make every effort to provide a calm environment for the epileptic patient.

Participant #11 (26-year-old young woman): *My mother and my brothers do everything they can for me. They want to do things to make me feel better and happier. They either talk or tell jokes until I laugh and feel happy.*

The main therapeutic and surveillance process prescribed by the medical team includes medication, patient's adherence to the treatment, hospitalization, medication dose adjustment, diagnostic testing, and surgical interventions as

indicated. The medical management of epilepsy is heavily focused on the medication and sporadically on holistic approaches.

Participant #21 (43-year-old woman): *I was glad when my daughter's physician told me not to give her water immediately after convulsion, wait until she feels a little better, her eyes have opened, only offer her water if she wants it and give her the medication immediately to prevent another convulsion.*

Healthcare providers prefer some changes in the medical management approach as stated by a physician:

Participant #25 (50-year-old doctor): *We understand that medication is not one hundred percent effective. We use the medication to solve the problem and often ignore the rest of the needed care and no one seems concerned. These issues must be resolved and addressed through consultations, patient guidelines and education to correct their attitude toward medical treatment.*

Struggle for equilibrium

Patients have to use certain strategies to find equilibrium and common grounds while maintaining their identity. Lack of community awareness about epilepsy and the stares threatened patient's self-identity and strategies had to be made to educate and inform the public about epilepsy and improve their attitude toward patients. Participants struggled to find information on epilepsy and learn how to keep their identity intact. The available resources were other epileptic patients, physicians, epilepsy journals, medical books, seminars, and the epilepsy association.

Participant #21 (43-year-old woman): *I participated in two seminars offered by the epilepsy association. They were good. The physician who spoke about epilepsy gave us good information.*

The role of faith and religious beliefs was recognized as the most important coping strategy. Participants strongly relied upon their faith to find tranquillity and acceptance of their disease, as religious beliefs gave them hope.

Participant #8 (34-year-old woman): *Now, anything that happens, I regard it as the will of God. I come to terms with it and I do not fight it.*

Participant #1 (22-year-old young woman): *I also try to accept that my disease will always be with me, and I trust in God that someday I may recover.*

Community awareness was a strategy favored by all participants as a key factor to preserve self-identity.

Participant #3 (22-year-old young woman): *Constructive cultural changes have to be made to improve the public's attitude about epilepsy, so that I can find a job somewhere and openly say "I am an epileptic" without hesitation. We need better understanding of this disease to hire patients, offer them a lighter and less risky assignment, matched with their ability and diagnosis; instead of rejecting them. Public awareness and education is a crucial strategy.*

Participant #5 (60-year-old man): *Unfortunately people look at epilepsy in a dim light. In my opinion, we need to increase the public awareness about epilepsy through conferences, publications, radio and television.*

Burn out

In relation to accepting their fate and coming to terms with their diagnosis, none of the participants admitted full acceptance and surrender to their diagnosis. For most of the participants, ineffective disease management led to the sense of helplessness and burn out. Here, the comments were "I cannot do anything anymore" and "the strategy of maintaining self-identity is useless."

Participant #1 (26-year-old young woman weeping): *I have run out of options because of my disease. The disease has badly affected my life.*

Participant #21 (43-year-old woman): *I got tired, I surrendered, I feel damaged by the disease, it has affected my nervous system and I have lost patience.*

Ineffective control

Although some of the participants relatively succeeded in controlling their seizures, the social label continued to haunt them with a sense of self-abasement, shame, and feeling disgraced. Participants spoke about the shame of having epilepsy and its permanent scars.

Participant #2 (25-year-old man): *I cannot come to terms with myself or stop wondering why my friends who were at my level or even lower are now ahead of me. Then I convince myself this is my fate. And again, with another fit, I go through the same self-pity process.*

Participant #9 (24-year-old young man): *I try to adapt myself to the community and be strong, and yet another fit occurs and puts me back on the first point again. I start all over again as this cycle continues.*

Helplessness

From participants' narratives, we concluded that distraction, fear of unknown and spiritual agitation formed a sub-category, i.e. helplessness. Participants rebelled with anger for the ineffective control of epileptic seizures and

medication side effects. They feared social labels and different glances in the community, threat to self-identity, and medication side effects.

Participant #31 (28-year-old woman): *It affects the human spirit. It badly affects human life. It weakens a person from inside... Somehow it breaks a person from the inside. Even if that person is strong, he is affected.*

They were sad and even contemplated suicide. Four of the participants repeatedly spoke about attempting suicide.

Participant #3 (26-year-old young woman): *I am often thinking of marriage and the fact that I am suffering from epilepsy, whether I get married or not, whether my secret is exposed or not weighs heavy on my mind. At least three or four times I have attempted suicide. I am very tired of life. I often beat myself.*

Participants spoke about feeling hopelessly tired of living and wished to die. They expressed a constant fear of being injured, hurting themselves, and dying.

Participant #21 (43-year-old woman): *Sometimes I get very tired and sometimes I am discouraged about life, because I have not recovered from this disease.*

Participant #2 (25-year-old young man): *Last night I was in a fearful state. Previously I said to myself that I am not afraid of these things, but I was in a situation that I was afraid. Previously I had said that I am not afraid of death, but last night I was really afraid of dying.*

DISCUSSION

Participants' experiences in this research showed that social labels, lack of public knowledge about epilepsy, and the nature of disease itself threatened their self-identity with each seizure. Telford et al.^[15] and Hosseini et al.^[3] believed that chronic diseases have a negative effect on self-identity. Participants in this study also had a sense of self-abasement and threat to self-identity. Walsh and Crumble found experiences of shame, loss of self-regard, and contempt from others among their study participants.^[3,16] Comparing the results of this study with the results of other studies on chronic diseases, we found that social labels and threat to self-identity were more pronounced among the Iranian patients with serious consequences.

Identifying the problem was recognized as the first step to manage the issues. Sentiments and perceptions found in this study revealed that efforts were required to protect the patient's identity and help them rebuild their identity as the main and central variable. In this regard, Aujoulat et al.

found that for maintaining previous identity, patients must imagine their disease as an enemy with whom they must fight.^[17] But Kralik *et al.* conceptualized the process differently by focusing on recovering the identity as an effort to becoming normal again.^[18] In comparison with other studies,^[7] our study showed that participants used concealment strategy at a higher rate. According to the Link's hypothesis, individuals facing stereotypes and stigma often apply a coping strategy by keeping low profile, remaining incognito and away from the community.^[19]

Participations, family members, and the medical team agreed that some degree of supervision was always required to prevent injuries. Patients in this study chose the cooperative self-management approach to assist their families and comply with the medical treatment. In qualitative studies, cooperative supervision and self-management plan, in addition to the patient's compliance were necessary for managing chronic diseases.^[7,20] However, using this model for epilepsy patients according to Bellon *et al.*'s epilepsy management plans, also termed "care plans" or "support plans," involves collating information on the individual's healthcare needs and documenting how family and support staff should respond and support the individual to achieve their personal goals such as social inclusion and management of their epilepsy in a single document.^[21] We found greater family support and less medical guidance for patients, compared to other studies. It is necessary for the medical staff to recognize the psychological and social aspects of epilepsy, in addition to providing medical treatment. The study on Iranian epileptic patients by Hosseini *et al.* identified a substandard chain of medical management by neurologists, as their treatment plans did not include psychological, social, cultural, and financial considerations for patients and their families and showed strong resistance to change.^[22]

The other coping strategy for maintaining self-identity was finding equilibrium. Participants searched for information on self-protection and integrated intellectual stand against the challenges to accept their diagnosis. Searching for information to recover self-identity was similarly reported by Killınc and Campbel when patients with epilepsy confront with identity threatening to try restoring identity by learning about seizure triggers and their control.^[23] Also, Baskind and Birbeck,^[24] Snape *et al.*,^[25] and Hosseini *et al.*^[22] reported participants' preference for public education on epilepsy. They reported public education was the best approach to reduce social labels and improve the quality of life of epileptic patients. Based on these findings, education for individuals, families, and the community through media could effectively increase public awareness on epilepsy,

improve patient management, and change the attitudes with less labels and shame for patients with epilepsy.

In this study, patients did not easily adapt to or accept their disease, and later learned that acceptance could bring equilibrium and preserve self-identity. Quantitative and qualitative studies in other countries have shown different results in relation to using adaptive strategies for epileptic patients. Some studies have advocated effective coping should include fighting the disease, seeking information, and finding support, while more studies have suggested strategies that are ineffective.^[7] By increasing patient awareness on effective coping methods and teaching skills for better coping, the medical team would have a better opportunity to manage epilepsy.

Contrary to the results of this study, Cooper *et al.* found that patients suffering from intestinal inflammation used self-adaptation approach^[26] and Kralik reported that patients in the last stage of a chronic disease had experienced a sense of normalcy with their disease.^[27] But in the first stage, we found that patients wanted to recreate a new self to avoid identity loss and later they discovered an identity of self-depreciation and helplessness. Also, the results showed that Iranian patients suffered more deeply from social labels and shame, and some of the coping techniques proved ineffective. According to Jacobi and Snape, in accordance with Gaffman theory, the labeled individuals try to get rid of any threat to their social identity; but once a person is labeled, the deep scars will remain, making it difficult to regain a normal life.^[19]

Clarke and Games found that individuals suffering from chronic fatigue syndrome move between two types of identity reconstruction, which include absence and disorder in the previous identity and acquiring a new identity or a new self.^[28] In a phenomenological study by Whitehead on patients with chronic fatigue and chronic bone infection, three stages of threat to identity were found and efforts were made to identify and reveal a new self or positive self. Individuals acquired a new sense of being a normal individual.^[29] Although these studies showed that patients can acquire a new and positive self, we found the threat to self-identity continued and different management strategies were needed to help patients accept their disease.

Limitations of this research include the following: (1) The interviewers were worried about seizures occurring during patients' expression of their emotions in a few interviewees which could lead to the termination of the interview. So, some feelings and emotions were blocked. The researcher interviewed these cases many times. (2) Many patients did not give consent for interview with their families because they were ashamed of having epilepsy.

CONCLUSION

We conclude that the central variable identified in the early process of disease management was the perception of identity interruption as a basic psychosocial issue and the main aspect recognized was threat to identity. Problem identification is the initial step for finding solution and in this case, it helps the healthcare providers find a way to address patients' needs by creating a patient education plan to supervise a self-managed chronic condition. By offering information and changing the community's attitude, significant improvements can be made to eliminate stereotypes and social labels. Through coping techniques, patients can learn to accept themselves as a human being and protect their personhood. Encouraging family members of patients to be assertive when assisting patients can provide the needed support for medical and personal care. Government funding could help support patients with their medical expenses. The results of this study could initiate subsequent multidisciplinary studies involving medicine, nursing, sociology, psychology, and other specialties for finding a comprehensive plan to help patients with epilepsy. Also, the results of this research provide some information about the management process of epilepsy in the social context of Iran, which could be helpful for better and more effective supervision of nurses, and especially contribute to create independence among patients with epilepsy. The findings of this research provide evidences for the various important roles played by nurses, including educator for patients, family, and community; counsellor; consultant; case manager; advocate; collaborator; and coordinator. So, nurses who have prominent roles should include in their nursing care plan patients with epilepsy, their family, and community.

ACKNOWLEDGMENTS

This study was part of an approved PhD dissertation with the proposal number 387061 at the Isfahan University of Medical Sciences. Researchers would like to express their sincere gratitude to the Isfahan University Medical Sciences and Health Services for all their support and cooperation with the implementation of this project. Also, the researchers are grateful to the study participants including patients, neurologists, nurses, officials, and staffs at the Isfahan University Medical Center and to all the organizations who collaborated with the research team.

REFERENCES

- McCagh J, Fisk JE, Baker GA. Epilepsy, psychosocial and cognitive functioning. *Epilepsy Res* 2009;86:1-14.
- Jacoby A, Wang W, Vu TD, Wu J, Snape D, Aydemir N, *et al.* Meanings of epilepsy in its sociocultural context and implications for stigma: Findings from ethnographic studies in local communities in China and Vietnam. *Epilepsy Behav* 2008;12:286-97.
- Hosseini N, Sharif F, Ahmadi F, Zare M. Patients' perception of epilepsy and threat to self-identity: A qualitative approach. *Epilepsy Behav* 2013;29:228-33.
- Aliasgharpour M, Dehgahn Nayeri N, Yadegary MA, Haghani H. Effects of an educational program on self-management in patients with epilepsy. *Seizure* 2013;22:48-52.
- Hovinga CA, Asato MR, Manjunath R, Wheless JW, Phelps SJ, Sheth RD, *et al.* Association of non-adherence to antiepileptic drugs and seizures, quality of life, and productivity: Survey of patients with epilepsy and physicians. *Epilepsy Behav* 2008;13:316-22.
- Hosseini, N, Sharif F, Ahmadi F, Zare M. Striving for balance: Coping with epilepsy in Iranian patients. *Epilepsy Behav* 2010;18:466-71.
- Edward K, Cook M, Giandinoto JA. An integrative review of the benefits of self-management interventions for adults with epilepsy. *Epilepsy Behav* 2015;45:195-204.
- Fraser RT, Johnson EK, Miller JW, Temkin N, Barber J, Caylor L, *et al.* Managing epilepsy well: Self-management needs assessment. *Epilepsy Behav* 2011;20:291-8.
- Sattoe JN, Bal MI, Roelofs PD, Bal R, Miedema HS, van Staa A. Self-management interventions for young people with chronic conditions. A systematic overview. *Patient Educ Couns* 2015;98:704-15.
- Shegog R, Bamps YA, Patel A, Kakacek J, Escoffery C, Johnson EK, *et al.* Managing epilepsy well: Emerging e-Tools for epilepsy self-management. *Epilepsy Behav* 2013;29:133-40.
- Sample P, Ferguson P, Wagner JL, Elisabeth Pickelsimer E, Selassie AW. Experiences of persons with epilepsy and their families as they look for medical and community care: A focus group study from South Carolina. *Epilepsy Behav* 2006;9:649-62.
- Streubert H, Carpenter D. *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Philadelphia: Lippincott Williams and Wilkins; 2007. p. 124.
- Munhall P. *Nursing Research: A Qualitative Perspective*. Philadelphia: Jones and Bartlett; 2011. p. 244.
- Corbin J, Strauss A. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 3rd ed. Thousand Oaks, CA: Sage; 2008. p. 73.
- Telford, K, Kralik D, Koch T. Acceptance and denial: Implications for people adapting to chronic illness: Literature review. *J Adv Nurs* 2006;55:457-64.
- Walsh M, Crumble A. *Watson's Clinical Nursing and Related Sciences*. London: Baillière Tindall; 2007. p. 726.
- Aujoulat I, Marcolongo R, Bonadiman L, Deccache A. Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Soc Sci Med* 2008;66:1228-39.
- Kralik D, Koch T, Price K, Howard N. Chronic illness self management: Taking action to create order. *J Clin Nurs* 2004;13:259-67.
- Jacoby A, Snape D, Baker GA. Epilepsy and social identity: The stigma of a chronic neurological disorder. *Lancet Neurol* 2005;4:171-8.
- Lake AJ, Staiger PK. Seeking the views of health professionals on translating chronic disease self-management models into practice. *Patient Educ Couns* 2010;79:62-8.
- Bellon M, Pfeiffer W, Maurici V. Choice and control: How involved are people with epilepsy and their families in the management of their epilepsy? Results from an Australian survey in the disability sector. *Epilepsy Behav* 2014;37:227-32.

22. Hosseini, N, Sharif F, Ahmadi F, Zare M. Disease-based versus patient- based approach in epilepsy management from the patients' point of view: A qualitative research. *Life Sci J* 2012;9:1983-90.
23. Killınç S, Campbell C. It shouldn't be something that's evil, it should be talked about": A phenomenological approach to epilepsy and stigma. *Seizure* 2009;18:665-71.
24. Baskind R, Birbeck GL. Epilepsy-associated stigma in Sub-Saharan Africa: The social landscape of a disease. *Epilepsy Behav* 2005;7:68-73.
25. Snape D, Wang W, Wu J, Jacoby A, Baker GA. Knowledge gaps and uncertainties about epilepsy: Findings from an ethnographic study in China. *Epilepsy Behav* 2005;14:172-8.
26. Cooper JM, Collier J, James V, Hawkey CJ. Beliefs about personal control and self-management in 30-40 year olds living with Inflammatory Bowel Disease: A qualitative study. *Int J Nurs Stud* 2010;47:1500-9.
27. Kralik D. The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *J Adv Nurs* 2002;39:146-54.
28. Clarke J, James S. The radicalized self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome. *Soc Sci Med* 2003;57:1387-95.
29. Whitehead L. Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study. *Int J Nurs Stud* 2006;43:1023-31.

How to cite: Hosseini N, Sharif F, Ahmadi F, Zare M. Determining the disease management process for epileptic patients: A qualitative study. *Iranian J Nursing Midwifery Res* 2016;21:54-62.

Source of Support: Isfahan University of Medical Science and grant number 387061, **Conflict of Interest:** The authors have no conflicts of interest.