

**Original Article**

**Perspective of people with epilepsy about Epilepsy**

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**Abstract**

**Objective:** This study aims to define epilepsy patient perspective about epilepsy. **Material & methods:** Phenomenological hermeneutic approach is used by emphasizing on van Manon (2001) method. In this study participants have chosen by targeted sampling. Semi structured interviews as well as observation have deployed for data collection **Results:** Patient's perspective explored by main four themes including: dumb concept, destructive agent of present and future's life, the cause of social isolation and divine punishment. **Conclusion:** Epilepsy is a disorder which is bounded by ambiguity and unawareness among patients and societies. The disease also known by them as an incurable and destructive disease, present and future's life destructive element, the cause of social isolation, divine punishment and atonement for sins.

**Keywords:** Epilepsy; perspective; phenomenology; hermeneutic; nursing; Iran

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**Background**

Epilepsy is a common chronic neurological disease the second cause of central nervous system disorders worldwide after stroke<sup>1</sup>. Epilepsy is severe transient mental or motor dysfunction due to intensive and sudden electrical discharge among a group of brain cells<sup>2</sup>. Clinical manifestations are different from epigrammatic decrease in the level of consciousness to complete seizures with sensory and psychomotor symptoms<sup>3</sup>. Epilepsy is the first neurological disorder in the world by prevalence rate between 1 to 5 percent. Epilepsy is more prevalent either because of increasing the number of epileptic patients or higher life expectancy among them<sup>4-5</sup>. There are 50 million people living with epilepsy in the world, of who up to 80% live in developing countries. Around 1% of total population of United States (about 2 million people) is living with epilepsy according to epidemiologic studies. The incidence rate of epilepsy in the developing country is about 40 to 70 per each 100,000 people annually<sup>6</sup>. Mostly, the

prevalence of epilepsy has reported 4 to 10 per each 1000 people<sup>7</sup>. This prevalence rate is around 1.8% in Iran<sup>8</sup>.

Patient with epilepsy suffers from physical and mental problems which sometimes are going to be severe even permanent. These chronic issues can be controlled by anti-epileptic medicine. Such medication may cause long term adverse effects which can be included to other socioeconomic difficulties<sup>9</sup>. Epilepsy affects patient's psychosocial life. Patient with epilepsy is mostly influenced by psychosocial consequences rather than disease by itself. Studies have revealed that patients with epilepsy have low income, low quality of life, social stigma, low self-confidence. Difficulties in adaptation have seen in 75% of patients as well<sup>10</sup>.

Another aspect related to epilepsy is cultural problems<sup>11</sup>. Patient's close relatives avoid being in touch with patient's family. They even see epilepsy as a harmful dangerous disease which can ban any social contact such as marriage with patient and

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family. Such avoidance or pity behaviors may put the patient's family in serious trouble culturally as well as socioeconomically<sup>9</sup>. Therefore patients and their families mainly complain about social perspective and cultural encounter rather than disease side effects and treatment costs. Families also complain about patient's physical deterioration along with social problem. Epilepsy extremely decreases the quality of life by its chronic nature as well as its mental, physical and social consequences<sup>1</sup>.

The destructive effects of epilepsy due to social stigma have been considered in the last two decades. Social environment is very stressful for these patient. Knowledge and attitude of the people about epilepsy is different according to their education, gender and age. Lower social class has got less knowledge and more negative attitude toward epilepsy<sup>1</sup>. According to all these mentioned socio-cultural difficulties due to public viewpoint, this study aims to assess and explain patients' perspectives about their own disease in order to respond to the curious question of the researchers in this field.

### Method

Phenomenological hermeneutic approach used for this study by emphasizing on van Manon(2001) method<sup>1</sup>. Participants had been chosen by targeted sampling<sup>2</sup>. Semi structured interviews as well as observation was deployed for data collection in this study. Face to face interactions with interviewees were carried out. Patients with epilepsy voluntarily and knowingly participated in this study. Those who were willing to take part in the study were interviewed. Previous conducted studies were used to set up general questions for current research objectives along with other qualitative professional's views. Then patients, families and care takers were visited to build up trusts and making agreements for upcoming interviews. We were informing families either by phone or in person few days beforehand to make them prepared for the interviews. Interviews usually were starting based on the interview guide by short introduction, brief explanation about the objectives after taking informed consents. Interviewees were assured about maintaining confidentiality. Interview environment was either patient's house or university regarding to patient's request. Conversations and dialogues were recorded during interview. Observation was used to note behaviors and non-verbal communications. All these information were used while scripting the interview and data analysis. Totally 12 participants were interviewed (5 patients and 7 family members). Average allocated time

for each interview was between 42 to 97 minutes. Recorded interview was accurately listened several times right after that. The content of each interview was transferred word by word. Then author reviewed each transcript by its related recorded interview (dialogue with transcript) to ensure more mastery over information. During semi structured interview or right after that, unstructured observation was used to note behaviors, non-verbal communications, personal gesture, facial expression and eye contact among participants. All these information were utilized for transferring interviews and data analysis. The method of analyzing phenomenological data was conducted based on van Manon (2001) phenomenological activities. In this method the first step stands for reflection about the inherent themes that explores the characteristics of the phenomenon. This step aims to do inherent analysis in order to obtain main themes<sup>14</sup>. This kind of analysis contains some activities such as separating thematic statements, changing and converting said statements, collaborative analysis, and distinction between inherent themes and subthemes. Holistic approach, highlighting approach and detailed or line by line approach were used to split thematic statements. It means that the text of each interview was considered as an integral part and its fundamental concept was defined in a clause firstly. Then related descriptions of that concept were chosen from each participant. Finally each interview was read and coded line by line.

To convert said statements some of the statements were changed to the cognitive terms or paragraphs in terms of brightening up the phenomenon. Author planned questioning as van Manon (2001) has recommended to distinguish between inherent themes and subthemes. Questions such as: If I change or remove these themes from the phenomenon hypnotically it will be remained as it was before? Whether phenomenon loose its fundamental meanings or not? Subthemes were deleted by this approach. At the stage of phenomenon description, author developed the text of phenomenology that was represented findings of the current study by writing and rewriting the themes, memos, descriptions about statements, expressing some of the participants' statements.

**Ethical clearence:** This research was conducted by permission issued from Ethics Committee of Nursing and Midwifery Faculty of Qazvin University of Medical Sciences, Qazvin, Iran.

## **Findings**

From 12 interviews, 12 general descriptions were done by using van Manon (2001) holistic and selective approaches. These descriptions helped author to extract more themes during selective analysis. At this stage, themes and subthemes related to perspective toward the epilepsy were extracted. Main four themes were including dumb concept, destructive element of present and future's life, the cause of social isolation and divine punishment.

### **Unawareness about epilepsy**

Although patients and families have no idea about epilepsy before their involvement with the disease but rejection or not taking it serious are the reasons to postpone gathering more information about it. It may cause some negative consequences. Unawareness about epilepsy as the main theme has three subtheme including unfamiliarity with the disease, rejection and not taking it seriously.

### **Unfamiliarity with the disease**

There are many people who don't know much about epilepsy though they have enough access to information. They may get information when they face with the disease. These people see epilepsy as hereditary incurable illness. Some may think brain infections will cause epilepsy and other might see some of the environmental factors like air pollution as its reason. One of the participants says:

"I never knew about epilepsy, I didn't know what it is"

The other participant with two years experiencing the disease says:

"...there must be something like a hand book, brochure, whatever, soon I'll take it because I need to know about epilepsy, but I didn't find anything about it ... there are many patients who don't know about their disease"

### **Rejection**

Epileptic patients and their families deny the diseases and try to ignore it. Treatment can be delayed by neglecting the disease. These patients also escape to admit their differences with healthy people and insist to continue their previous life style. Since accepting the epilepsy means changing the life, patients continue to live their lives as it was before. One of the participants says: "after a while I realized that it is getting worse, they asked me to do MRI, and then they said you have to do injection prior MRI, so I did it, I couldn't accept that I have got epilepsy."

### **Not taking seriously**

Some of the patients do not take the disease seriously they do not even put any efforts for following up their

treatments. One of participants says:

"I was taking my pills irregularly; I said to myself that I have no problem, these people are making it difficult...I wasn't taking it seriously"

### **Destructive factor of present and future's life**

Chronic nature of the disease and its destructive consequences affect patient's whole life. This fact has explored as themes including tension, stress and obstacle to progress.

### **Tension and stress**

Epilepsy puts a lot of pressure on patients and their families. Patients endure a lot of stress. Financial crisis is one of those pressures. One of participants says:

"...well... costs are high, I am a tenant and I'm renting a shop, the situation is like ...I can't bear that, covering the expenses are difficult for me. I have insurance, I am paying for that 2,100,000 Rial monthly but for example this Luber pills that I bought is out of insurance coverage. With to your service I am under pressure"

Patients could be facing too much pressure, feeling such as shame and even committing suicide when they would have difficulties to accept their differences with normal people. One patient talks about this issue:

"epilepsy is all about stress... stress even doesn't leave me alone... when I have seizure in front of other people and when I always think that nobody should know about that ...stress will come spontaneously."

### **Obstacle to progress**

Patients lose many of their opportunities in present and future life. They rarely could get a job and in the most cases are becoming jobless. Patients may leave some of their interests giving up can be definitely painful for them. They will see this failure as a result of their disease. One of the participants says:

"I really liked my car, all of the sudden I was told that I couldn't get in and it was too much for me. Or for example once when I was with my friends I had seizure, what happened! Once I was on footstool in a shop; shopkeeper took me down, my body is loose and bored, my mood is cluttered."

Marriage is one of the things that may be influenced by epilepsy. Married patient may get divorce and some of them may not be able to get married at all. People avoid marrying with these patients due to fear of inheriting the disease. A young woman states:

"...for a girl epilepsy means forgetting about marriage, could you have a good marriage? Meanwhile it is not all about marriage itself...it goes beyond that."

### **Social isolation factor**

Isolation is the most common feeling that patients experience in their own life due to social viewpoints and stigma. When patients stay away from others as result of negative feelings caused by epilepsy isolation can be exacerbated. Losing opportunities and being forced to leave life interests are other reasons for isolation. One of patients expresses this feeling as below:

"I'm known badly in the society...one can say something to others...I will be fired out of work for sure...no one hires an epileptic patient...most of the time it is obvious... even family, wife and children want to hid you behind because of their exclusion fear."

#### **Divine punishment**

Some of the patients may see the epilepsy as their own divine punishment or atonement of their sins. These patients are always looking up their past and becoming more and more isolated by blaming themselves. This is a faulty cycle in patient's mind. One of the patients says:

"...epilepsy is a big exam... as if god is testing you... maybe it is punishment for your bad things...I have no idea...I think we will receive atonements of our sins in this world"

#### **Discussion**

Findings of this study show that patient's perspective about epilepsy depends on social relations and culture of the society. The impact of culture on perspectives toward epilepsy along with impact of different social group characteristics on that have been studied earlier and even a model has been designed in order to explain such perspective<sup>16</sup> as such individual perspective forms based on personal and social context<sup>17-18</sup>.

Some of the participants in this study believed that epilepsy meant social isolation due to lack of proper social communication. The most important challenge for the patient is social stigma. This finding has revealed through other studies as well<sup>19-20</sup>. It is hard to take care of these patients because epilepsy means social isolation for them and their relatives. Loneliness and seclusion can be provoked via lack of attention due to getting excluded from family<sup>21</sup>.

The main reason of hopelessness among patients and their families is social unawareness about epilepsy. People might lead patient with epilepsy toward social isolation by getting them surrounded by superstitions instead of providing enough support during seizure attack. Patients suffer from such perspectives even

avoid to get married in some of the cases<sup>22-23</sup>. Maybe this refusal has originated from a fear of genetic transmission of epilepsy<sup>24-25</sup>.

Patients with epilepsy see their disease as an incurable illness that is making them feel as burden to others, taking them apart from their social life. Neither they are able to struggle with the situation nor community able to support. So patients become frustrated and look at epilepsy as their life destructive factor.

This study is different from previous literatures because of its exclusive finding such as divine punishment theme. Epilepsy never has been seen as the atonement for sins so far. Therefore divine punishment can be considered as a new concept in perspective toward epilepsy. Patients see their illness either as a consequence of their own sins and faults or a way coming from god to resolve their mistakes. Some believe that epileptic patients are chosen to be purified by god first and leave this world at the end of the day. Some think that epilepsy is a result of great sins which leads patients to repent and atonement subconsciously. Such an idea will cause more isolation for the patients and take them away from social environment<sup>26-27</sup>. Based on the findings of this study patient's perspective about epilepsy can be presented as below:

Epilepsy is a disease bounded by ambiguity and unawareness among patients and community which has seen by them as devastating fatal illness, destructive factor for their present and future's life, the cause of social isolation, divine punishment and atonement for their sins.

Patient's insufficient perspective about epilepsy makes it difficult to adapt with the diseases. Such viewpoint will represent epilepsy as a destructive factor to the entire patient's life. Patients get away from social life and interacting with other people via such negative feelings. Negative consequences are even worse when patient thinks about atonement and punishment for sins. Treatment must be planned via a holistic approach considering physical, mental, social and spiritual components.

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