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Quality of Life Epilepsy Patients' in Indonesia

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Abstract

The quality of life of epilepsy patients is different from the quality of life of the people in general. Epilepsy patients are required to take medication every day for a long time. Epileptic seizures that appear suddenly also become an obstacle and cause embarrassment and worry to the sufferer. The purpose of this study was to find out about the quality of life of epilepsy patients in Indonesia. The research method used was qualitative methods with a descriptive phenomenological approach, data collection was carried out through individual in-depth interviews for seven

participants. Data analysis used thematic analysis and the results obtained were four themes related to dimensions of quality of life. Four themes emerged from the findings as follow: Information about disease, Perceived quality of life, Social Transformation, and Access to health services. The study showed that the quality of life of epilepsy patients is in a good condition if they are assisted by treatment, good health facilities and patient adherence to treatment as prescribed.

Keywords: Epilepsy, Quality of Life, Patients

Introduction

Epilepsy is a chronic disease that attacks the head and can be found at all ages. The population of active epilepsy (patients with uncontrolled seizures or those who need treatment) is estimated to be between 4 and 10 per 1000 population per year (Beghi & Sander, 2008) ^[3]. The active epilepsy population is estimated at 6 to 10 per 1000 population (WHO, 2012). The total population of Indonesia in 2013 was 244,814,000, so it is estimated that the active epilepsy population in Indonesia is 1.5-2.4 million people (BPS, 2013).

Epilepsy can be experienced by every individual. This is due to the causes of epilepsy which are very diverse such as brain injury, poisoning, stroke, infection, parasitic infections and brain tumors. Epilepsy can occur in various sexes, both men and women in various age ranges. Global data collection found 3.5 million new cases per year of which 40% were children and around 40% adults, and another 20% were found in old age (Purba, 2008) ^[6].

Epilepsy is a health problem that is a medical problem as well as a social problem. It becomes a medical problem because epilepsy is a neurological disease that requires strict medical management and supervision in its treatment (Pinzon, 2011). It becomes a social problem as stated by Argyriou *et al* in Primadi and Hadjam (2010) ^[5] that the psychosocial problems of epilepsy patients are caused by several factors, including from the epilepsy disorder itself, from the side effects of the treatment being undertaken and the latter is indirectly a consequence as a person. living with epileptic disorders. This is because there is still a social stigma about epilepsy. This negative stigma is often a stressor that is more dominant than medical or psychological factors. This social label can exacerbate problems in people with epilepsy.

Stigma and myths that develop in Indonesian society create a misunderstanding that epilepsy is not a disease but rather a magical power, curse, possession and often even said to be a mental illness. For this reason, many epilepsy patients choose not to disclose their status for fear of being considered a disgrace in society. As a result of the various misunderstandings that arise, epilepsy patients are worried that this will close their opportunities to obtain proper education and work (Muttakin, 2008) ^[7].

Epileptic patients have a lower quality of life than normal people (Pinzon, 2007) ^[4]. Various consequences of the diagnosis of epilepsy received by these patients which then make the quality of life of epilepsy patients decrease and are limited by various things. The research conducted by Hawari (2005) which was conducted on 145 respondents, showed that low level of education, frequent seizure attacks and types of polytherapy treatment were strongly related to the low quality of life of epilepsy patients.

Methods

Design

The type of research is qualitative research, with a phenomenological approach. This approach was chosen because in this study the researcher wanted to see the quality of life of people suffering from epilepsy so that researchers could explore the depth and complexity of the dimensions of quality of life in people with epilepsy, the method used in this study was descriptive phenomenology. This research was conducted by doing In-depth interview and participant observation as the method.

Setting

This research held in the regional hospital in Aceh. The hospital consists of 15 specialist polyclinics, 13 inward rooms and 4 intensive care rooms. Every month the hospital serves around 5000 outpatients with an average of around 2000 patients visiting the Neurology Polyclinic every month. The Neurology Polyclinic at hospital serves various types of patient illnesses such as epilepsy, stroke, low back pain and other diseases related.

Participants Recruitments

The participants of the study were recruited by using purposive sampling. The researcher interviewing seven people with epilepsy as participants in this study with the characteristics of having epilepsy for more than 6 months with various types of seizures, having EEG results showing abnormal waves (sharp wave or spike wave), understanding Indonesian and being able to speak Indonesian, domiciled in Banda Aceh, willing to be a respondent by giving informed consent.

Data Collection

In qualitative research, the research instrument is the researcher himself (human instrument), where the researcher is a data collector who will dig for deeper information about the participants (Moleong, 2006). Data collection tools in this study were interview guides, field notes, and tape recorders. The method of data collection that will be used is planned with a semi-structured interview method.

Before data collection, the researcher tested the researcher's ability to conduct interviews and the effectiveness of using tools in the interview process. The implementation of the instrument tryout was carried out on 2 participants, this instrumented test was to see the researcher's ability to communicate effectively, test the participants' understanding of the questions, test the researcher's ability to fill out field notes, as well as consider the distance of the voice recorder so that the sound recording process was heard properly.

Then, the researcher reconfirmed the time agreement that had been made by the researcher and the participants in the previous stage. The researcher collected data through face-to-face in-depth interviews with questions designed to explore the meaning and significance of the quality of life of epilepsy patients. The interview began by asking for identity then the researcher gave questions according to the interview guidelines. Researchers also develop open questions related to research objectives until the researcher considers all questions have been answered. Interviews were conducted with each participant for 30-40 minutes.

In the next stage, the researcher immediately made a transcript of the interview so that it became verbatim (word for word). The verbatim also includes field notes. This was

done by the researcher to ensure additional completeness as well as a basis for selecting the next participant. Before compiling the interview transcripts, the researcher first listened to the interview recordings in full and read the field note sheets. Before terminating, the researcher confirmed the results of the data analysis that had been obtained from the participants. The researcher shows the results of the thematic analysis that has been produced from the interview transcripts to the participants to get approval or clarification if there are inappropriate data. If all the transcripts are correct, the researcher terminates the participants by stating that their participation in this research is complete. Researchers provide rewards in the form of thanks to participants for being willing to take the time to follow the research.

Data Analysis

The research data used the data analysis technique of the Collaizi model (1978 in Polit & Beck, 2012). The steps include: 1) Read all interview transcripts to get a feel for the participants; 2) Review each transcript and draw conclusions from any significant statements; 3) Describe the meaning of significant statements; 4) Grouping these meanings into theme groups; 5) Integrate the results into a descriptive form; 6) Make a complete description of the phenomenon under study as an identification statement as firmly as possible; 7) Validate what has been found to the participants as the final validation stage.

The data analysis was performed under periodic consultations with the research team members who were also the thesis advisors. All researchers participated in the systematic data analysis after data collection was completed. The researchers tried to intuit what the participants actually shared beyond the words transcribed, carefully looking for the patterns of their experience, and conducting a number of discussions to develop the coding frame. The discussions highlighted and resolved the areas of disagreement to reach a final coding frame to code the entire data set. The initial themes, subthemes, and meanings were reviewed by the research team to ensure the credibility and saturation of the data.

In this study, credibility, dependability, confirmability, and transferability were applied to achieve the trustworthiness of the data. To ensure the credibility of the research findings was proven by collecting all data from participants using the interview method, analyzing it, then the researcher consulted with the thesis advisors to check the data and returned to the participants to ask them to assess the truth of the data whether it was by what they said or not. The data was collected using observation and in-depth interview. Associate participants were also involved to achieve triangulation. The strategy to achieve dependability was to conduct an inquiry audit by an external reviewer to evaluate the findings. Confirmability was also established through member check and peer debriefing technique.

Result

After analyzing the seven steps according to Collaizi, 4 themes were identified, namely, (1) Information about disease, (2) Perceived quality of life, (3) Social Change, and (4) Access to health services.

Information About Disease

Information about the disease includes several sub-themes,

namely the definition of epilepsy, seizure frequency, seizure duration, position when seizure happen, and duration of treatment.

Regarding definition of epilepsy, participants stated that epilepsy is a disease of seizures, as in the following participant statement:

".....epilepsy is seizures... basically it makes people unconscious, convulsions hhhmm.. after that it makes us...(pause for a moment) mentally miserable.." (Informan 1, female, 25 y.o)

"...I don't know epilepsy, but I'm being treated here because of seizures..." (Informan 2, male, 30 y.o)

"....I don't understand what epilepsy is because the doctor said epilepsy but what I know is that I'm taking medication because I often have seizures while sleeping..." (Informan 4, female, 17 y.o)

".....I don't know what epilepsy is, basically I just often have seizures without being conscious like that..." (Informan 6, female, 18 y.o)

"...epilepsy is a disease of convulsions..." (Informan 7, male, 18 y.o)

In addition to their understanding of epilepsy, participants also stated that their seizure frequency was quite frequent. This is shown by the following statements:

".....in this year there have been seizures twice, last month there was once sis, this month there was once..." (Informan 1, female, 25 y.o)

".....sometimes once a month, sometimes more..." (Informan 2, male, 30 y.o)

".... last month 7 there was a seizure mom said, but I don't know because I don't feel it...." (Informan 4, female, 17 y.o)

"....in this month, this is the first time I have had a seizure...last year there were also seizures..." (Informan 6, female, 18 y.o)

"....in a week I had four seizures..." (Informan 7, male, 18 y.o)

The duration of the seizure was also disclosed by the participants. This is indicated by the following statements:

"....no one saw it but yesterday my mother saw my body slammed like that, it took about half an hour..." (Informan 2, male, 30 y.o)

"....about three minutes or five minutes..." (Informan 4, female, 17 y.o)

"....not long, just a few second..." (Informan 7, male, 18 y.o)

The length of treatment was also disclosed by the participants with various length of treatment. This is indicated by the following statement:

".....it's been a year and a half..." (Informan 1, female, 25 y.o)

"....it's been 11 years..." (Informan 2, male, 30 y.o)

"... it's been 5 years..." (Informan 3, female, 20 y.o)

"....hmmmm...2 years..." (Informan 7, male, 18 y.o)

Perceived Quality of Life

Perceived quality of life includes several sub-themes, namely self-esteem, spiritual support, and assessment of

quality of life.

"....ashamed to be honest...ashamed of my friends if my friends know that they feel inferior..." (Informan 1, female, 25 y.o)

"...It's a shame..." (Informan 2, male, 30 y.o)

"....we realize that Allah has given us this trial, there will definitely be a silver lining behind all of this and maybe Allah will love this so that I will be closer to Allah..." (Informan 3, female, 20 y.o)

The assessment of the quality of life is related to the participant's assessment of his life. This is in accordance with the statements of the following participants:

"....It's almost good because there is one step that I couldn't achieve, namely continuing my education, for others, we can say that it has been achieved..." (Informan 1, female, 25 y.o)

"....Anyway, it's pretty good sis.. Not one hundred percent okay.. Almost okay..." (Informan 2, male, 30 y.o)

"....Good..." (Informan 3, female, 20 y.o)

Social Transformation

Social transformation includes two sub-themes, namely social supports and inhibiting factors. This theme relates to the participant's relationship with the people around him. This is in accordance with the statements of the following participants:

"....if the family is very motivating, it's okay to just take medicine so that it heals, but other people don't know because I've never told anyone..." (Informan 1, female, 25 y.o)

"...so my friends stay away a bit..." (Informan 2, male, 30 y.o)

"....It's fine..if I'm invited to work together in the village, I will come and join..." (Informan 7, male, 18 y.o)

The inhibiting factor is because epilepsy patients feel they have limitations due to their illness, as expressed by the following participants:

"...So I will get tired easily, if i push too hard I'm afraid it will go down later and it will go limp.. that's all.. then I feel most anxious after yesterday..." (Informan 1, female, 25 y.o)

"....in the past, before i got sick, I was dream to get high achievements, but since I was sick, it has changed..." (Informan 3, female, 20 y.o)

"... it's hard to catch a lesson now..." (Informan 7, male, 18 y.o)

Access to Health Services

This theme relates to easy access to health care centers. This is in accordance with the statements of the following participants:

".... it's affordable..." (Informan 1, female, 25 y.o)

"...It's not difficult..the facilities are good..." (Informan 2, male, 30 y.o)

Discussion

Information about Diseases

The participants' experience and knowledge about epilepsy varied widely. Information about epilepsy is needed so that participants can take good care of themselves and be able to avoid things that are considered capable of triggering seizures. The frequent frequency of seizures appeared to make participants feel worried and anxious about doing activities so that this had an impact on various aspects of life. This is in accordance with the study of Shetty *et al*, 2011^[14] which revealed that epilepsy patients have significant physical and emotional trauma which has limited their activities with a lack of attention. Epileptic patients also worry about seizures, fatigue, impaired memory and hopelessness of health. They were also worried about the long-term side effects of anti-epileptic drugs and the length of treatment also disrupted the participant's quality of life because he felt bored and bored with the routine treatment he was undergoing, as stated by several participants.

Perceived Quality of Life

The participants' assessment of their quality of life aims to enable participants to assess their lives in accordance with the understanding they understand, the level of quality of life of the participants is quite diverse but relatively the same, namely they say that their level of quality of life is not very good because they are still constrained by health problems. This is in accordance with research conducted by Hawari (2005) which showed that out of 145 respondents, his research showed a low quality of life. This is influenced by the patient's worry and anxiety about epileptic seizures that appear suddenly and the frequency of epileptic seizures that come.

This was also reinforced by research conducted by Salsabila (2012) which stated that the quality of life of epilepsy patients in early adulthood underwent changes involving self-adaptation and self-acceptance factors. Factors that affect the quality of life of epilepsy patients include family circumstances, economic factors, employment opportunities, anxiety and stigmatization. Anxiety is the biggest factor that determines the quality of life of epilepsy patients.

Social Transformation

Social change includes interpersonal relationships, namely relationships between individuals and other individuals. The family's view of the participants was quite good and they even continued to support and motivate the participants not to give up and continue their treatment program. The opposite was found by the participants from the views of their friends that there were participants who felt that they were starting to be isolated and not included by their friends because they were worried that at any time the participants might have a seizure.

Some of the participants revealed that their epilepsy made them have to give up their dreams to achieve a higher level of education and a better job. It was felt by the participants that they were no longer able to achieve their dreams because intellectually and physically they became weaker. Some of the participants also revealed that they were afraid and hesitant to start a household because they were worried that no one would accept them in this condition. This is in accordance with research conducted by Salsabila (2012)

which revealed that stigmatization by the people around them makes epilepsy patients worry about continuing their education and also do not dare to step into marriage.

Access to Health Services

Access to health care is also important in the quality of life of epilepsy patients, because those who have access to good and smooth health facilities will routinely monitor their health developments so that they will be able to complete the stages of treatment which can have an impact on improving their health condition and the frequency of seizure attacks. which is happening less and less.

Conclusions

This study shows that the quality of life of epilepsy patients is in a good condition if they are assisted by treatment, good health facilities and patient adherence to treatment as prescribed.

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