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Patients' perception of epilepsy and threat to self-identity: A qualitative approach

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ABSTRACT

Introduction: A clinical diagnosis of epilepsy often carries a silent social stigma and is associated with metaphysical forces. This qualitative study aimed to explore the Iranian patients' perception of epilepsy where clinical aspects are more benign than the social implications with long-term psychological consequences. Historically, epilepsy has been known as a form of insanity, madness, sorcery, and possession by evil spirits.
Method: Thirty participants consisting of 21 patients with epilepsy, 5 family members, and 4 medical staff were selected from urban and rural medical and health care centers, hospitals, physician offices, outpatient clinics, and the Iranian Epilepsy Association. Unstructured and semistructured interviews were applied to obtain data. Transcribed interviews and field notes were analyzed using qualitative content analysis method.
Findings: Categories and subcategories emerged from the participants' perceptions of epilepsy and its disruptive effects on their self-identity. The main categories derived from data were 1) a different perspective about epilepsy, 2) self-debasement, and 3) being a burden. The major theme found in this study was "identity loss".
Conclusion: Our study results highlight the importance of public awareness among community members and healthcare professionals on how patients with epilepsy experience their disease with psychosocial implications. Understanding patients' perspectives can be essential to developing a comprehensive and holistic care plan for patients with epilepsy and addressing their multidimensional needs.

1. Introduction

Epilepsy is one of the most prevalent neurological disorders with a global patient population of 95–100 million [1] and rising at a continuous rate annually [2]. In a published metaanalysis, the average worldwide prevalence of epilepsy had an overall rate of 4.8 to 49.6/1000: 15.4/1000 in rural areas and 8.2 to 37.7/1000 in urban areas. In a study by Mohammadi et al., an epilepsy prevalence rate of 1.8% among 25,180 Iranians over the age of 18 years was reported [3].

Epilepsy contributes to financial, social, physical, and psychological difficulties for individuals, families, and the communities [4]. The disease also creates restrictions and problems in lifestyle, family life, marriage, employment, academic progress, driving, and economic status for the patients [5–7].

Throughout history, epilepsy has been viewed with some degree of social stigma in developed and developing countries [5,8]. As a clinical condition, epilepsy also has a cultural component affecting multiple aspects of an individual's life [9] with devastating lifelong consequences for the individual and family members [10]. Most patients and family members find the social aspects of epilepsy more undesirable than its clinical management [11]. The psychosocial effect of epilepsy includes a high prevalence of mood disorders such as suicide tendency and social isolation [12,13]; a sense of shame and sin [14]; and low self-esteem, anxiety, depression, and pessimism [15].

Macleod and Austin found that labels attached to epilepsy initiated low self-esteem, agitation, and negative life sentiments among the patients [15]. These sentiments intensified threat to healthy self-identity in patients with epilepsy. Also, Jacoby et al. stated that social labels provoked negative and profound reactions among patients with epilepsy to the extent that it threatened all aspects of their self-identity [6]. Disabilities associated with the chronic state of epilepsy often generate self-doubt that damages an individual's identity [16]. Similarly, in a quality-of-life study on adolescents with epilepsy in Glasgow, Scotland, Townshend et al. discovered negative identity perceptions and sentiments among the young patients [17].

Although the aforementioned studies indicate identity disruption in patients with epilepsy, we found no comprehensive investigation in Iran or other countries addressing the sociocultural aspects of epilepsy. In fact, we determined that the Iranian cultural diversity necessitates a qualitative investigation of patient perceptions and how epilepsy has changed many aspects of their lives or how the chronic

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state of the disease has influenced their self-perceptions. It seems crucial to know patients' experiences to provide the most effective treatments, patient education, and health promotion—not only for the patient population but also for their families and community they live in. Recognizing epilepsy as a physical, social, psychological, emotional, intellectual, and clinical entity could help better treat and control seizure episodes and improve patients' quality of life.

2. Methods

2.1. Method of sampling and patient selection

Of 30 participants, there were 21 patients with epilepsy, 5 family members of the patients, and 4 medical staff. The participants were recruited and selected during October 2009 through December of 2010, using a goal-oriented sampling method. The sample selection took place and continued at the urban and rural medical centers, hospitals, physician offices, clinics, and the Iranian Epilepsy Association until data saturation.

2.2. Method of collecting data

The participants were individually interviewed at the location of their choice (home, workplace, park, etc.) for an average of 75 min and between one to three sessions. Data were collected using in-depth, unstructured and semistructured interview methods. As the participants shared their experiences, body language and other expressions were observed and noted. The interviews began with a general question ("please tell me how being diagnosed with epilepsy has influenced your life") and gradually moved to more specific topics. The participants consented to having the conversations recorded after being assured that their information would be kept private and confidential.

Data credibility, accuracy, validity, and reliability were established through continuous comparative analysis to search for similarities and contrasting cases. Sufficient time was allocated for data collection and matching interview contents with those observed and further communicated with the participants for clarity. Data were coded and recoded after multiple reviews. Deciphered codes were reviewed by expert colleagues familiar with qualitative research. The criterion for conformability or generalizability of the research results was implemented, and research audit was conducted by an external reviewer to assure data reliability.

2.3. Data analysis method

Content analysis method allows researchers to find hidden meanings in obtained data at various stages starting with primary coding, review, and continuous verification. In this study, the primary researcher reviewed the recorded data immediately after each session and again read the transcribed interviews line-by-line within 24 h of data collection. Key concepts were coded and stored in a Microsoft Word file. Later, merged and summarized codes were grouped and categorized for concept similarity and contrasts. The same pattern of classification continued for every category on all previously coded concepts until secondary groups were formed as subcategories within the main categories. Concepts were specified based on peculiarities and joint dimensions. Later, common patterns were extracted, and the intended phenomenon was identified. Again, data were coded and recoded until categories and subcategories representing the participants' perceptions were formed.

2.4. Ethical consideration

This research study was approved by the ethics committee at the Isfahan University of Medical Sciences. All the participants signed an informed consent prior to enrollment in the study. The participants were assured of their anonymity and confidentiality. The voluntary enrollment with the ability to refuse or withdraw from the study without any penalty was emphasized.

3. Results

3.1. Findings

The three main categories identified were 1) a different perspective about epilepsy, 2) self-debasement, and 3) being a burden. The main theme from the categories was "loss of identity" (see Table 1). The narrative details of participant perceptions and data classifications also revealed deep emotions related to discrimination and social rejection. Stigma and self-debasement were viewed as different aspects of epilepsy where gradual progress of identity loss and a sense of being a burden to self, family, and society were initiated.

3.1.1. A different perspective about epilepsy

Raw data were overwhelmingly focused on the social labels, perception of discrimination, and social rejection. On the first review and second open coding process, the fear of stigma was most prevalent and formed a subcategory. The social labels stereotyped, stigmatized, and made the patients with epilepsy feel discriminated against. They sensed public rejection and, subsequently, lost belief in themselves and questioned their identity.

The initial experience of being diagnosed with epilepsy was very disturbing for our participants and was described as "my whole world crashed and I knew that for the rest of my life I have to live in shame with a social stigma". The patients were afraid of being labeled and did not want to face strange looks or hear whispers that followed them like a dark shadow. Their fear of stigma was intensified by the fear of having a seizure attack in public that could devastate their self-esteem, reputation, and social identity and followed by a life of shame and indignity. The participants openly described their mental breakdown when they heard their diagnosis.

> P 12: with my first seizure attack, my whole world crashed because people look at an epileptic person very differently (27-year-old woman).

The community has a negative view of epilepsy, and people react differently toward this disease. The general reactions are exhibited by stares and pity where patients feel ashamed. There is a permanent fear like a dark shadow threatening their social identity. A participant explained her fear of having an attack in public and her sense of shame and disgrace as follows:

> P 21: I am afraid of having a seizure attack and feeling sick in the presence of someone I know and if I sense feeling unwell I prefer to be in my house with my family rather than in the presence of

Table 1
Perceptions of patients with epilepsy.

Main theme	Category	Subcategories
Loss of identity	I) A different perspective about epilepsy	1—Fear of stigma 2—Perceived discrimination 3—Social rejection
	II) Self-debasement	1—Perception of indignity 2—Dissipated prestige 3—Loss of self-esteem
	III) Being a burden	1—Not living a normal life 2—Employment insecurity 3—Educational setback 4—Economic hardships