



Felt and enacted stigma in elderly persons with epilepsy: A qualitative approach



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ARTICLE INFO

Article history:

Received 20 September 2015

Revised 14 December 2015

Accepted 16 December 2015

Available online 13 January 2016

Keywords:

Elderly

Epilepsy

Stigma

Qualitative

ABSTRACT

Stigma is a common psychological consequence of chronic diseases, including epilepsy; however, little research has been done to determine the effect of stigma on persons with epilepsy, especially the elderly. We interviewed 57 older adults with epilepsy to discover the extent and consequences of, and reasons for, epilepsy-related stigma in their lives. Felt stigma was more frequently reported than enacted stigma, with over 70% having experienced this form of stigma. Participants described ignorance and fear of the disease as the foundation of epilepsy-related stigma. The most common response to stigmatizing events was a decrease in epilepsy disclosure to family or friends. Results from this study could inform interventions designed for elderly persons with epilepsy and their support networks, as well as educational campaigns for the general public.

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1. Introduction

Epilepsy is a chronic brain disorder characterized by recurrent seizures caused by abnormal neuronal excitation [1,2]. The disorder affects at least 2.3 million adults in the United States alone, approximately 1.0% of the adult population [1]. The elderly are especially affected: 1.2% of adults over age 60 years are living with epilepsy [3]. There is also a higher incidence of newly diagnosed epilepsy in this age group compared with other age groups [4]. This cohort also experiences increased levels of comorbid challenges such as physical injury, loss of confidence and independence, and anxiety and depression [5–8]. Epilepsy can also carry a great deal of stigma for those affected, regardless of age, which can lead to higher levels of mental illness as well as lower levels of self-esteem, confidence, and self-respect [9–11].

1.1. Stigma

Stigma is defined as a loss of social status due to the possession of an attribute that one's culture sees as “undesirably different [and] deeply discrediting” [12]. It can be broken down into two components: felt and enacted. Felt stigma refers to the fear of experiencing epilepsy-related stigma, while enacted stigma refers to an actual episode of epilepsy-related stigma [13]. Any number of attributes or conditions can be stigmatizing, including chronic diseases such as epilepsy [11]. Epilepsy, in particular, goes against social norms such as control and predictability, as seizures can arise dramatically, without warning, and

despite a person's efforts to prevent them [9,10,14]. While some studies report that persons with epilepsy (PWE) feel less stigma than initially thought [15,16], the majority found epilepsy to be a stigmatizing disorder, and as such, has social and health-related consequences that include poor mental health and a lower level of social support [17–21].

1.2. Purpose

The impact of stigma upon overall quality of life in PWE has been examined extensively in adolescents and middle-aged adults [9,17,22,23], but little has been done to examine these interactions in older adults with epilepsy. The aim of this study was to qualitatively assess the effects of stigma upon the quality of life of elderly persons with epilepsy.

2. Materials and methods

2.1. Recruitment

Individuals aged 65 years or older who had seizures or had been diagnosed with epilepsy and live in Southern Arizona were recruited between 2010 and 2013. Recruitment occurred through flyers, referrals, and public education sessions. Participants were reimbursed for their time and participation. This study was approved by The University of Arizona's Institutional Review Board (IRB00000291).

2.2. Data collection

Potential participants were sent a letter inviting them to participate in the hour-long in-depth interview, together with a consent form to

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review. They were then contacted by telephone, and an appointment was made if the participant was interested in taking part.

Project participants were informed at recruitment that they would be invited to participate in an in-depth interview. Interviews took place immediately for those who had a previous diagnosis of epilepsy, and six months after recruitment for those who had a new diagnosis of epilepsy. The six-month period provided the newly diagnosed participants some time to live with the diagnosis and its consequences before answering the in-depth questions. It was not necessary to impose this limitation on those participants who were diagnosed previously, as they were not newly diagnosed and had lived with the disorder for some time.

Individuals who had new-onset seizures or were diagnosed with epilepsy at or after age 65 years were surveyed by telephone at baseline (recruitment period) and again, every six months (follow-up interviews), regardless of the date of their in-depth interview to document changes that may have occurred (e.g., changes in residence, confirmation of seizure diagnosis, death). These follow-up interviews were 5- to 10-minute check-ins that did not include open-ended questions but also served as a way for the project to keep in contact with participants without being overly intrusive. The baseline survey included demographic information, seizure characteristics, and information about comorbid conditions.

2.3. In-depth interview process

Three interviewers conducted the in-depth interviews. A medical anthropologist (KR) interviewed participants who were diagnosed at age 65 years or older. Participants who had been diagnosed before age 65 years were interviewed by two project staff members who were responsible for all recruitment and baseline interviews.

The majority of participants were interviewed in person at their homes; four preferred alternative locations or methods (through the phone, participant office, interviewer office, or a coffee shop). Prior to the interview, the interviewer went through the informed consent procedure for the in-depth interview and asked for permission to audio-record the interview (except for the individual who was interviewed by telephone). The average length of the interviews was 41.8 min (range 15–128 min; sd 19.6 min).

Topics for the in-depth interviews included the impact of being diagnosed with epilepsy or seizure, social relations, coping with seizures, treatment, and resources sought. Questions relating to stigma included the following: “Before you had seizures, what did the terms ‘seizure’ and ‘epilepsy’ mean to you?”, “Now that you have seizures, what do they mean to you?”, and “What do you think the terms ‘seizure’ and ‘epilepsy’ mean to people in your community/culture?”. The complete interview guide is located in Appendix 1.

2.4. In-depth interview analysis

The recordings of these in-depth interviews were transcribed and checked for accuracy by a second transcriber. The transcripts were analyzed by three reviewers; each noted the responses to the questions posed and organized them into themes. The reviewers then discussed the themes to ensure consistency of coding. Once a consensus was reached, each interview was reviewed again to ensure that the interviews had been assigned the appropriate codes.

3. Results

3.1. Sample

In-depth interviews were performed with 57 participants. Table 1 provides a summary of their demographics.

The mean age of participants was 74 years, with the majority (73.7%) having received a diagnosis of epilepsy in their mid- to late-sixties. Only four participants were diagnosed prior to age 21 years. The majority of participants were married and lived with their spouse. There were

Table 1
Demographic characteristics of 57 study participants.

Variable	M (sd)	n (%)
Age (years)	74.08 (6.59)	
Age of seizure onset (years)	64.56 (20.86)	
Gender		
Female		36 (63.2)
Male		21 (36.8)
Marital status		
Married		34 (59.6)
Widowed		12 (21.1)
Never married		6 (10.5)
Divorced		5 (8.8)
Ethnicity		
Non-Hispanic		48 (84.2)
Hispanic		9 (15.8)
Living arrangement		
With spouse		34 (59.6)
Alone		11 (19.3)
With other family		6 (10.5)
With children		3 (5.3)
Other		3 (5.3)

significantly more women than men who participated; however, there were no significant gender-related differences in the number of participants who reported stigma, felt or enacted, although females were slightly more likely to report feeling both kinds of stigma.

3.2. Felt stigma

When asked what their community thought about epilepsy, over half (71.7%) of participants perceived felt stigma in their daily lives: “If you use the word epilepsy, it can be a stigma.” Another described that “the ‘E word’ [has] a lot of stigma attached to it.” Specific themes discussed regarding felt stigma included fear of others’ reactions, affects on work or social life, and an association with mental health.

A significant concern was the reaction their friends or acquaintances would have if told about their diagnosis. One participant stated, “I would think that when you tell [other people] that you have epilepsy, they get startled or frightened.” Another said she thinks that “people tend to be scared of [seizures].” The perception feared by most participants was one of a dramatic, generalized tonic-clonic (GTC) type seizure. Many participants worried that epilepsy is perceived “like somebody falling down, foaming at the mouth, twitching.” One man reported that, before his first seizure, he had “all the worst stereotypes... this really negative image of epilepsy” and was concerned that others might harbor the same stereotypes about his disease.

Some participants were concerned about epilepsy affecting their work or social life. One worried about what her friends would think if she had a seizure while on a social outing: “I know how upsetting seeing a grand mal can be...I’m not sure it wouldn’t upset the whole trip.” A participant who worked in finance reported, “I don’t tell my clients because they might doubt my abilities.” One man reported that “because professionally [he is] still active,” he decided to not disclose his disease. Another said she didn’t tell anyone about her seizures “because sometimes you’re afraid that if too many people know about it, it would get out and...you won’t get a job, you lose your job.”

Several participants mentioned a perceived connection with mental health and intelligence. One man described how “people look at you, I don’t know, I guess they consider you as being nuts.” Another said that having epilepsy “probably means you are a little crazy,” or that “you have mental problems that will be kind of bad.” One woman reported that “in our culture, I think, it is a sign of weakness...you are not as smart because you are sick.” A fourth participant summed up these concerns saying, “I have always wondered if they equate epilepsy as something to do with your mental state.”

However, there were participants who did not have any experiences of felt stigma. One man said, “I don’t think anybody thinks I am crazy, I

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