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Patient-centered outcomes in older adults with epilepsy

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ABSTRACT

Purpose: Older adults have the highest incidence of new-onset epilepsy, yet there is a lack of self-management interventions to ensure that this population achieves desirable outcomes. In order to develop patient-centered interventions for older adults with epilepsy, self-management outcomes of importance to these patients must first be explored. The purpose of this study was to describe what outcomes older adults diagnosed with epilepsy late in life hope to achieve in self-managing their condition.

Method: Qualitative description was used. 20 older adults took part in semi-structured interviews. Data were analyzed using conventional content analysis.

Results: Six themes emerged – Maintaining Normalcy, We Want to be Involved, Well-Equipped, Seizure Freedom, Fitting Epilepsy in with Other Conditions, Incongruence with Provider Goals.

Conclusion: These results add to the extant literature, and provide knowledge on which patient-centered epilepsy self-management interventions can be developed. In addition, these results can inform the development of a patient-centered outcome measure for older adults with epilepsy. Such a measure could be used in conjunction with existing measures related to disease status (seizure frequency, etc.) to ensure that outcomes pertinent to both patients and providers are targeted and measured.

1. Introduction

Globally, older adults have the highest incidence of new-onset epilepsy. In the United States (U.S.), 27% of annual epilepsy diagnoses involve those age 60 years and older.[1] European-based studies have also revealed that older adults are most affected by new-onset epilepsy.[2] The increasing life expectancy in developed countries ensures that the incidence of epilepsy in older adults will continue to escalate.[1,3]

Persons with epilepsy are charged with self-managing their condition, and thus contribute to attainment of epilepsy-associated outcomes[4–6]; the care of those with epilepsy must include preparation for epilepsy self-management. Epilepsy self-management refers to an interactive phenomenon in which patients continually evaluate their perceived health status (which comprises how they feel emotionally and physically and how they are able to function on a daily basis) and implement a variety of behaviors to manage their medications/treatments, safety, seizures, physical and emotional comfort, functional status, and other factors depending on their current perceived health.[5] Facilitating effective self-management is particularly important in older adults with epilepsy, including those who develop the condition late in life, given that their self-management is complicated by the existence of multiple comorbid conditions, polypharmacy, and age-related physiological and cognitive changes.[7,8]

Epilepsy self-management interventions aimed at improving outcomes for older adults with epilepsy, including those diagnosed in older adulthood, are not available.[9] A review of the literature reveals no published studies pertaining to the development or testing of epilepsy self-management interventions for older adults. In addition, relatively little research apart from that relating to medical treatment of the condition has been done with this population. There is a particular dearth of research involving older adults who have developed epilepsy late in life—the population most affected by new-onset epilepsy.

The published literature reflects no inquiries into the self-management process or outcomes of older adults with epilepsy. There is a need to generate such knowledge given the Institute of Medicine's[10] recommendation that programs targeting patient-centered outcomes to improve quality of life (QoL) in persons with epilepsy should be developed. The American Geriatrics Society[11] has also advocated for the use of patient-centered programs for

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older adults with multiple co-morbidities. Such programs cannot be developed for a population highly affected by epilepsy—older adults—without descriptive knowledge of their self-management experiences and desired outcomes. Additionally, such knowledge can be used to render existing interventions designed for younger adults with epilepsy, or even those designed for persons with other chronic diseases, useful to older adults with epilepsy.

Knowledge that exists regarding the epilepsy self-management of younger adults may not be wholly applicable to older adults given the uniqueness of this population in terms of epilepsy etiologies, clinical presentation, prognosis, and the common presence of multiple comorbidities, polypharmacy, and age-related cognitive and metabolic changes in older persons with epilepsy.[8] Therefore, epilepsy self-management interventions that have been developed based on research involving mostly younger adults may not be as pertinent to or effective for older adults managing epilepsy; moreover, effective epilepsy self-management interventions, even for younger adults, are sparse.[12] Recently, however, WebEase (Web Epilepsy Awareness, Support, and Education), a web-based epilepsy self-management intervention, has been shown to affect some patient outcomes, such as one measure of medication adherence, social support, sleep quality,[13] and self-efficacy[13,14] in adults with epilepsy. WebEASE was designed for adults, and was developed based on social cognitive theory, motivational interviewing, and the Transtheoretical Model of Behavior Change. The goal of WebEASE is to improve medication, stress, and sleep management.[14]

While WebEASE is a promising intervention for adults with epilepsy, it does not address the specific need for an outcome-improving intervention for older adults with epilepsy, and particularly those who are beginning to manage the condition at or after age 60. First, WebEase is not tailored to the needs of older adults with epilepsy, including those diagnosed late in life. Specific contextual tailoring of self-management interventions has been shown to be important.[15] Second, WebEase has been tested with older adults on a limited basis. In both trials in which the intervention was tested, the mean age of participants was much younger than age 60—37.5 years in one study ($N = 35$)[13] and 40.87 years in one study ($N = 148$).[14] While the authors reported that older adults were included in the samples via reporting an age range of participants—20–63 years[13] and 18–77 years[14]—the number of older adults who took part in these studies, and how many of those older adults had been diagnosed with epilepsy in older adulthood, is unknown. Third, the outcomes targeted by WebEase are somewhat limited and may not capture some outcomes important to older adults.

In order to develop data-based epilepsy self-management interventions for older adults with epilepsy, and to tailor existing interventions (such as WebEase) to this population, descriptive research is needed. The Patient Centered Outcomes Research Institute[16] has espoused the notion that behavioral interventions must impact outcomes that matter to patients—patient-centered outcomes. Thus, it is of particular importance that the outcomes important and relevant to older adults self-managing epilepsy are revealed. The purpose of this study was to describe what outcomes older adults diagnosed with epilepsy late in life hope to achieve in self-managing their condition. This purpose was pursued using a qualitative descriptive method.

2. Methods

2.1. Procedures and data collection

Approval of the study was granted from the appropriate Institutional Review Board. Participants were recruited from a regional neurology practice serving urban and rural areas in the Midwestern region of the U.S. The following inclusion criteria were used: (1) age 60 or older, (2) diagnosis of epilepsy at or after age 60, (3) diagnosis of epilepsy six months or more prior to recruitment, (4) community-dwelling, (5) prescription of at least one anti-epileptic drug (AED), and (6) able to speak and read English. Patients meeting the main inclusion criteria of being 60 or older and having been diagnosed with epilepsy at or after that time were identified by neurologists. Recruitment letters informing patients of the study were signed by neurologists and mailed to potential participants. The letters also informed potential participants that a researcher would be contacting them about the study.

Detailed recruitment activities have been reported elsewhere.[17] Fifteen participants were recruited. In addition, five participants whom had been recruited for a pilot version of the study several months earlier were also included in this study, bringing the total number of participants to 20.

Data collection took place via self-report using a face-to-face, audio-recorded interview with each participant. Interviews were conducted from February through August of 2011. Interviews of 19 participants were conducted in participants ‘homes, while one participant‘s interview was conducted in a meeting room in a library. Prior to interviews, demographic data were collected. Interviews were initiated using the following question, which was aimed at eliciting self-management outcomes pertinent and important to participants: ‘‘*What do you hope to achieve in self-managing your epilepsy?*’’. Probes, such as ‘‘*What outcomes are most important to you?*’’ and conversational interviewing were used in all interviews based on responses. Interviews ranged from 40 min to 2 h. Data collection continued until informational redundancy was met, which occurred after the 20th interview.

2.2. Data analysis

Descriptive statistics were employed to analyze demographic data. Interviews were transcribed and analyzed via conventional content analysis.[18] Analysis of transcripts occurred concurrently with data collection. Using Sandelowski's[19] guidelines as a starting point for analysis, the author and an additional researcher individually generated codes related to self-management outcomes important and relevant to participants. Each researcher yielded a coding scheme, and both schemes were compared. Any discrepancies were discussed, and changes were made to the scheme until agreement was reached. The scheme was tested against all data. Finally, codes were divided into clusters,[19] and themes were developed using a data matrix.[20]

3. Results

3.1. Sample

Twelve (60%) participants were female, and 8 (40%) were male. Nineteen (95%) participants were Caucasian, and 1 (15%) was African American. The age range was 60–80 years, with a mean of 70 years. Table 1 details demographic characteristics of the sample.

3.2. Themes

Six main themes, one including sub-themes, emerged as representative of outcomes of epilepsy self-management particularly important to participants. An additional theme related to participants' perceptions of their epilepsy care providers' goals of epilepsy management also emerged. All themes are presented in Table 2.