Epilepsy & Behavior 31 (2014) 152–159

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

A mixed methods analysis of support for self-management behaviors: Perspectives of people with epilepsy and their support providers

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ARTICLE INFO

Article history:
Received 13 September 2013
Revised 15 November 2013
Accepted 23 November 2013
Available online 8 January 2014

Keywords:
Epilepsy
Social support
Self-management
Rasch analysis
Mixed methods

ABSTRACT

Social support is associated with improved self-management for people with chronic conditions, such as epilepsy; however, little is known about the perceived ease or difficulty of receiving and providing support for epilepsy self-management. We examined patterns of epilepsy self-management support from the perspectives of both people with epilepsy and their support persons. Fifty-three people with epilepsy and 48 support persons completed a survey on epilepsy self-management support. Of these individuals, 22 people with epilepsy and 16 support persons completed an in-depth interview. Rasch measurement models were used to evaluate the degree of difficulty of receiving or providing support often for nine self-management tasks. We analyzed model-data fit, person and item location along the support latent variable and differential person and item functioning. Qualitative methods were used to provide context and insight into the quantitative results. The results demonstrated good model-data fit. Help with seizures was the easiest type of support to receive or provide more often, followed by rides to a doctor's appointments and help avoiding seizure triggers. The most difficult types of support to receive or provide more often were reminders, particularly for taking and refilling medications. While most participants' responses fit the model, responses of several individuals misfit the model. Person misfit generally occurred because the scale items did not adequately capture some individuals' behaviors. These results could be useful in designing interventions that use support as a means of improving self-management. Additionally, the results provide information to improve or expand current measures of support for epilepsy self-management to better assess the experiences of people with epilepsy and their support persons.

1. Introduction

People with chronic diseases, such as epilepsy, must employ strategies and behaviors to manage symptoms, slow disease progression, and maintain quality of life. Self-management behaviors for epilepsy include taking medication as prescribed, adjusting one's lifestyle to avoid seizure triggers, tracking seizures and side effects, keeping doctors' appointments, and obtaining information on seizures, treatment, and management [1]. Successful initiation and maintenance of self-management behaviors is difficult. Up to 40% of people with epilepsy (PWE) are considered nonadherent to their medications [2–4]. Nonadherence can have serious consequences, including increased mortality and hospitalizations [2,3,5], reduced seizure control [4,6], decreased productivity, job loss, and motor vehicle accidents [4,5]. However, PWE report greater self-efficacy for adherence to medication regimens than to other lifestyle behaviors, which is similar to individuals with other chronic conditions [7–9].

Social support is a key mechanism that aids individuals in managing chronic conditions [10,11]. For PWE, support is associated with greater self-efficacy for performing self-management behaviors [12,13]. Support persons provide reminders and monitor medication taking; assist PWE with strategies to help them take medication, reduce stress, and improve sleep; help before, during, and after seizures; and are key sources of emotional support (e.g., expressions of love and caring) and instrumental support (e.g., tangible aid or services) [14].

Social support and social ties have long been recognized to contribute to positive health outcomes [15–17]. Low social support in the general population is linked with greater activity limitation and disability, depressive and anxiety symptoms, poorer self-rated health, and decreased satisfaction with life [18]. However, support is a complex and multifaceted concept. Measures of social support assess a wide variety of support dimensions, including different types of support, perceived or actual support received, satisfaction with support, importance of support, and/or the positive or negative aspects of support. Some types of support may be easier or harder to receive or provide; likewise,

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http://dx.doi.org/10.1016/j.yebeh.2013.11.023

some types of support may be more or less necessary depending on the PWE and support persons. Additionally, the support relationship may be affected by the presence of depressive symptoms in PWE or the people who support them. Depression is associated with diminishing social support over time; people with depression experience a reduction in social network size and perceive less social support [19]. For the support person, a higher caregiving burden is associated with poorer mental health [20–22], which may in turn affect how support is provided. Little is known about these aspects of support for people with epilepsy, particularly from the perspective of the support person.

The purpose of this mixed methods study was to examine patterns of self-management support for PWE from the perspectives of both PWE and their primary support persons (PSPs). Specifically, our main aims were to evaluate the following: 1) which types of self-management support are easier or harder to give or receive consistently and 2) whether the items in the Epilepsy Regimen-Specific Support (ERSS) scale functioned in the same way for both PWE and PSPs and for individuals with elevated depressive symptoms compared with participants without depression. Secondarily, we evaluated the ERSS scale to determine if it included a full range of support items.

2. Methods

2.1. Design and sample

This study was part of a sequential mixed methods study that involved a quantitative phase followed by a qualitative phase. The purpose of the overall study was to examine the interpersonal relationship between PWE and PSPs and the effect of the relationship and support provided on epilepsy self-management. This analysis focuses on patterns of self-management support that emerged from the quantitative and qualitative data.

Following Institutional Review Board approval, participants were recruited from a hospital-based epilepsy clinic from April to November 2011. Inclusion criteria for participants with epilepsy included the following: 1) being 18 years of age or older, 2) having a diagnosis of epilepsy for at least 3 months, 3) being able to identify a primary support person, and 4) being able to speak and read English. Eligible PWE were asked to provide the name and contact information of their primary support person, defined as a nonpaid individual who provided or who would be most likely to provide support to the PWE. Primary support persons were eligible if they 1) were 18 years of age or older, 2) provided unpaid assistance to a person with epilepsy, and 3) spoke and read English.

Healthcare providers handed out fliers to interested patients, who could talk to the study staff in person at the clinic or call the number on the flier. The first author described the study to interested individuals and answered any questions. Participants had the option to complete the consent form in the clinic or at home and then return the form by mail. Data collection did not occur until the investigators received the signed consent forms.

2.2. Data collection

Participants completed a 15-minute survey, which was administered over the phone. In addition to marking the participants' answers, the researcher wrote down comments offered by the participants to explain their answers. At the completion of the survey, individuals were recruited through purposive sampling to complete an in-depth interview. Participants were selected to represent a range of self-management levels, support levels, and depressive symptoms. Interviews lasted about 60 min and were conducted over the phone. Participants were asked about five main topics: experiences with epilepsy, effects of epilepsy on the PWE's and PSPs' lives and relationships, characteristics of their interpersonal relationship, overall support provided to the PWE, and support specifically for self-management. All interviews were audio-recorded and transcribed verbatim. Participants received a $10 gift card for completing the survey only or a $25 gift card for completing both the survey and the interview.

2.3. Measures

2.3.1. Self-management support

Frequency of perceived available support for assisting with the completion of epilepsy-related self-management tasks was measured using the Epilepsy Regimen-Specific Support Scale [ERSS; 23]. The nine items assessed support provided through reminders (reminders to take medication, eat healthy meals, get enough rest, refill medication, and be careful in case PWE have seizures) and help (help bringing PWE to doctors, help when PWE have seizures, and avoiding things that cause seizures). The items were rated on a 5-point Likert scale from *never* (1) to *always* (5). People with epilepsy were asked how often the primary support person provides the support, whereas primary support providers were asked how often they provide the support to the PWE. Additionally, the PWE and PSPs were asked how often they think the PWE would like the support provider to give the support described in each of the items in the ERSSS.

2.3.2. Depression

The Center for Epidemiological Studies Depression Scale (CES-D) is a 20-item scale that was designed to assess current levels of depressive symptoms in the general population. Each item is rated on a 4-point Likert scale from *rarely occurs* (0) to *occurs most* or *all of the time* (3). Summed scores were dichotomized using the cutoff point of 16, which indicates probable depression [24].

2.3.3. Demographic information

Participants were asked to answer questions about their age, gender, race/ethnicity, marital status, living situation, education, employment status, and insurance status. People with epilepsy were asked how many seizures they had in the past 4 weeks and what type(s) of seizures they experience.

2.4. Rasch data analysis

Descriptive statistics were run using SPSS v.19, and Rasch analyses were conducted using the Facets program v.3.70.1. The Rasch measurement model is commonly used to assess psychometric properties of scales; in this analysis, we used Rasch modeling to examine patterns of support for self-management. The Rasch measurement model is an item response theory model that places individuals and items on a common metric so that they can be compared along a unidimensional latent variable. In this analysis, the latent variable is self-management support. The probability of a person endorsing a particular response is determined by two factors: the person's "ability" and the item "difficulty." The terms "ability" and "difficulty" derive from the origins of Rasch modeling in the education field, where the probability of responding correctly to a question is based on the person's ability and the difficulty of the question [25]. In applying the Rasch model to the case of support for self-management, the person's "ability" refers to the amount of support that PWE report receiving or that PSPs report providing. The item difficulty indicates the level of difficulty in receiving or providing support more often; higher item difficulty scores indicate that the support task is harder to receive or provide more often, and lower item difficulty scores indicate that the support task is easier to receive or do more often.

For the Rasch analysis, we used a rating scale model because each item of the ERSS had five response options [25]. The items from the ERSS, assessing perceptions of support received and provided, as well as perceptions of support the PWE would like to receive, were entered into the model. Rasch measurement models include several facets or variables. A facet was included for each of the following: participants'