Published in final edited form as:

Epilepsy Behav. 2014 February ; 31: 152–159. doi:10.1016/j.yebeh.2013.11.023.

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

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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.

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Keywords

epilepsy; social support; self-management; rasch analysis; mixed methods

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 and instrumental support [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, 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 (PSP). Specifically, our main aims were to evaluate: 1) the types of self-management support are easier or harder to give or receive consistently; 2) whether the items in the

Epilepsy Regimen-Specific Support (ERSS) scale functioned in the same way for both PWE and PSP and for individuals with elevated depressive symptoms compared with participants without depression. Secondly, 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 PSP 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: 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. PSP 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 PSP's 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). PWE 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 PSP 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. PWE 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 PSP 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' reported level of support received or provided, difficulty in endorsing an item, an identifier as being a PWE or a PSP, and classification of having probable depression or not. The model can be written as follows:

$$\text{Ln} [P_{nik}/P_{nki-1}] = \Theta_n - \delta_i - \alpha_1 - \Delta_1 - \tau_{ik}$$

where:

P_{nik} = the probability of participant n endorsing answer choice k on an item i ,

P_{nki-1} = the probability of participant n endorsing answer choice $k-1$ on item i ,

Θ_n = the level of social support provided or received for participant n ,

δ_i = the difficulty of item i , and

α_1 = the group effect (PWE or support provider)

Δ_1 = the depression effect

τ_{ik} = the difficulty of responding in category k relative to $k-1$ on the rating scale

The Facets software provides summary and fit statistics for each facet and also displays the results in the form of a variable map. The variable map is a visual representation of each facet along the latent variable of support for self-management. The person mean varies along the latent variable, whereas the other facets are anchored at zero to provide a frame of reference. Facet separation reliability indicates the overall separation, or spread, of the components in each facet. The person separation reliability coefficient is considered to be equivalent to Cronbach's alpha, a measure of the internal reliability of the scale, and is viewed as acceptable at values over 0.7 [25].

The fit of the model to the data was evaluated through Infit and Outfit statistics, which should fall within the range of 0.6 to 1.4. Values above 1.4 indicate that the data include greater variability than expected based on the model, whereas values under 0.6 indicate less variance than expected based on the model [25].

Person functioning was examined by identifying individuals with Outfit mean square statistics below 0.6 and above 1.4. For these participants, whose responses “misfit” the model, standardized residual plots were created to identify responses that contributed to the misfit with a standardized residual above 2.0 and below -2.0 .

Differential Item Functioning (DIF) occurs when item location along the latent variable changes based on person sub-groups; in other words, when there is an interaction between items and sample characteristics [26]. DIF analyses were conducted to determine if the support items were ordered differently based on: 1) whether the individual was a PWE or support provider, and 2) whether or not the participant experienced high levels of depressive

symptoms. Evidence of DIF can be found if the overall chi-square test is significant; if so, t-tests comparing the average scores between groups are examined.

2.5. Qualitative Data Analysis

Transcripts were uploaded into qualitative software (MaxQDA) for data management and analysis. Data analysis was guided by the constant comparison method commonly used in grounded theory [27,28]. A codebook was developed through two approaches: 1) deductive (identifying initial codes from the interview guide and the literature) and, 2) inductive (identifying salient themes and concepts from the narrative). All transcripts were independently coded by two researchers. The coding was compared for consistency, discrepancies were discussed, and transcripts were recoded as necessary. No major discrepancies in coding were found. Analysis of the transcripts focused on grouping codes into meaningful categories and examining the relationships between concepts and themes [27,29]. Themes relevant to the quantitative analysis were reviewed for this study.

3. Results

3.1. Sample

One hundred and one individuals (53 PWE and 48 support providers) completed the survey. The sample comprised 47 complete PWE/supporter pairs, 6 unpaired PWE, and 1 unpaired support provider. Of these participants, 38 individuals (22 PWE and 16 support providers) completed an interview. The interview sample comprised 14 complete pairs, 8 additional PWE, and 2 additional support providers. The majority of the participants was female, white, lived with family, and completed at least some college (see Table 1). PWE tended to be single and either unemployed or on disability, whereas most PSP were married and working. About 40% of PWE and 30% of PSP had probable depression.

3.2. Variable Map and Model-data Fit

Figure 1 displays the variable map, which shows the calibration of facets (persons and items). The first column is the logit scale, which serves as the common ruler on which persons and items are placed. The next two columns show the location of PWE and PSP on the logit scale. For PWE, persons who perceived receiving more support are closer to the top, whereas persons who received less support are at the bottom. Similarly, PSP who reported providing more support are closer to the top.

The next two columns show the location of items along the support latent variable. Types of support that were easier to provide or receive more often are at the bottom. Help with seizures was the easiest type of support to receive or provide more often. This means that people reported often receiving or providing help for seizures starting at a lower threshold of overall support. Types of support that were more difficult to provide or receive more often are located toward the top of the column. Reminders about taking and refilling medication were the hardest types of support to receive or provide more often. This means that PWE and PSP had to report receiving or providing a high level of support in order to say that they often received or provided reminders.

The variable map provides information about the spread of persons and items, indicating the degree to which the facets are aligned. When a sample and scale items are aligned, the person and item facets should be spread similarly across the logit scale. PWE are located between about -1.0 and 2.0 logits, and PSP are located between about -1.0 and 1.0 logits. The items range from about -1.5 to 0.6 logits. Overall, there is a good overlap between persons and items, which suggests that the items are calibrated well to the population. However, there are no items that overlap with PWE who receive higher levels of support or PSP who provide higher levels of support (above $.6$ logits).

The Rasch model summary statistics, including mean location on the latent variable and fit statistics for each facet, are shown in Table 2. There is good model-data fit based on the mean Infit and Outfit scores for each facet, which are close to 1. The standard deviations for the person and item fit statistics are above 0.2, which is higher than expected and indicates some misfit. The standard deviations indicate that there is additional variance in the model, which is most likely due to persons not responding as expected. In response to this finding, we looked to the qualitative data to help explain the extra variance; these results are described in Section 3.4.

The reliability of separation is good (above 0.7) for both persons and items. The significant reliability of separation for the dyad facet indicates that the mean location of PWE and PSP on the latent variable is different. PWE reported receiving more support, on average, than the PSP reported providing. There is also a difference in the mean location of individuals who have probable depression compared with those who do not. On average, individuals who were not depressed reported receiving or providing more support compared to people who had elevated depressive symptoms.

The Rasch measures accounted for 43.6% of the variance. Values above 20% indicate an acceptable unidimensional scale for Rasch analysis [30].

3.3. Qualitative Support for Variable Map

Data from the interviews and comments that participants made during the surveys provided context and insight into the ordering of items. Results from the interviews supported the ordering of the items, where seizure support was easier to receive and provide more often and reminders were more difficult.

3.3.1. Seizure Support—PWE and PSP spoke extensively about the support that was provided before, during, and after a seizure. The support person performed a variety of support tasks such as monitoring PWE's symptoms and behavior, making sure PWE remained safe during a seizure, and caring for them during the post-ictal state when the PWE may be experiencing fatigue, confusion, or headache. The amount of support provided depended on the type and severity of seizures, with tonic-clonic seizures requiring more care than other types. This is illustrated by the following quote from a mother of a young woman who experienced two types of seizures that she described as “small” and “big”.

[The “small” seizures are] very concerning, of course, because she kind of loses coordination and her speech is slurred... We'll lay her down, and she kind of pulls

out of it... So that's not too bad. When she has the big ones, it is more stressful... I just lay her down and stay with her and, you know, just try to make sure she just doesn't hurt herself or anything.

3.3.2. Driving to Doctor's Appointments—Driving the PWE to the doctor was another type of support that was easy for PWE to consistently receive and for the PSP to provide. All of the PWE were unable to drive at some point, either currently or in the past, depending on if their seizures were controlled or not. In almost all cases, both the PWE and PSP stated matter-of-factly that the support person drove PWE to the doctor when they could not drive, without positive or negative emotion attached. It appeared that this is a prioritized task that simply must be accomplished.

3.3.3. Avoid Seizure Triggers—The majority of pairs described ways in which the support person helped the PWE to avoid seizure triggers. The most common triggers were lack of sleep and stress; thus, PSP reminded PWE about going to bed at a good time and discussed ways to manage stress. Ways in which PSP aided the PWE in stress management included providing emotional support, talking with the PWE, and completing household tasks or errands. A husband with epilepsy described what his wife did to help him manage stress:

She tries to make sure that it's a non-stress or stress-free zone here. Explain to me or just stop talking to me when she sees that we're having a conversation and I'm getting frustrated because I got lost somewhere along the way or I'm not getting it. Or she'll say, "We'll just pick this up later."

The participants' experiences demonstrated that support for trigger management encompassed several of the scale items, including help avoiding triggers, reminders to rest, and sometimes reminders to eat healthy.

3.3.4. Reminders—The qualitative data also supported the finding that reminders were more difficult for some PWE and PSP to receive and give more often. PWE had varied reactions to reminders, which were commonly about taking medication or getting enough sleep. Many PWE felt that the reminders were beneficial, while others expressed annoyance and frustration, especially when they saw the reminders as unnecessary because they were already performing the behavior adequately. For example, a daughter expressed frustration with her mother's reminders about medication:

It doesn't bother me that she reminds me, it's just like, what she does it's like sometimes like, "Yes mom I know, leave me alone." ...So just sometimes it's annoying because I know what I need to do and she is just like, "Hurry up, do it, do it." I take it at seven every night and it will be like 7:06 and it is like, "Mom, six minutes late is not going to affect me."

In several cases, PWE felt ambivalent about reminders. One PWE stated the following about her husband reminding her to take her medication, "I mean, it's good that he's asking me, you know, reminding me. But sometimes he reminding me a bit too much... It gets on my nerves."

Support providers also expressed some frustration when they felt that they needed to make sure that the PWE took their medication, but the PWE were not receptive to their efforts. One mother said about her son who has epilepsy:

But I'm the one that he calls, you know, into the room to help him when he has a seizure. But then at the same time, he wants me there, but he doesn't want me saying anything like, "Are you sure you took your medicine?" or "Why didn't you take your medicine?"

For some PSP, reminding the PWE to take medication was seen as part of the role of being a wife or a mother. According to one mother:

I nag her. About did you take your medicine. Isn't that a mother's job - did you take your medicine? You know did you clean your room? Did, you know, the usual stuff. Nothing special because I think it's up to her to manage her own gig.

3.3.5. Other Support for Self-Management—The types of support provided sometimes went beyond what was captured by the scale items. In addition to reminding PWE about a doctor's appointments or driving the PWE to the clinic, several PSP called the doctor or accompanied the PWE to appointments in order to inform the doctor about the PWE's condition. This usually occurred when the PWE was unable to communicate to their doctor what was going on because they were unconscious during seizures or experienced cognitive or memory difficulties. A woman with epilepsy described the need for her mother to provide this support:

She is the one that always calls the doctors when something is going on, especially with my meds. Because she can be the first hand, because I don't know I'm having my seizures. She's the one that sees it and is just like, ok, no, this shouldn't be happening. She is the one that will go and call the doctors and see what is going on and what we should do to make it better.

Some PSP also kept a record of when the PWE had seizures in order to provide doctors with detailed information.

3.4. Person functioning

Out of 101 participants, 66 had Outfit mean square statistics inside the expected range of 0.6 to 1.4, which indicates good model-data fit. Eighteen individuals had an Outfit mean statistic less than 0.6, indicating less variation than expected, and 17 had an Outfit mean statistic greater than 1.4, indicating more variation than predicted by the model. To identify the reasons for excess variation, we examined the standardized residuals of the 9 participants with the greatest misfit (Infit and/or Outfit > 1.8). Each of the 9 individuals had from 1-3 responses where the standardized residual was less than -2.0 or greater than 2.0 (see Table 3).

3.4.1. Qualitative Support for Person Function—Reviewing the qualitative data to explain the excess variation, we found that individuals' circumstances caused them to respond in a way that did not fit the model (see Table 3). In two cases of misfit for the item on reminders to refill medication, the model predicted that the PSP would remind the PWE

often to refill their medication, but the PWE responded that this was not the case. Reminders were not given by the PSP because either the support person refilled the medication themselves or the pharmacy automatically refilled the prescription (Table 3: PWE 5 and PWE 6).

For the item on support during a seizure, the model predicted that a woman would often provide support to her husband (Table 3: PSP 3). However, he only had experienced a few seizures since his diagnosis, and she had never been with him when he had a seizure; therefore, she answered “never”. For another PWE (Table 3: PWE 3), her support person lived in a different state and provided very little support for her self-management, generating low scores on most items. However, on the survey she responded that he does sometimes remind her to take her medication when they are together, though they only see each other about once a year.

In one misfit case, a female participant's (Table 3: PWE 1) survey responses conflicted with her interview responses. She said that her mother “never” reminded her to take her medication or to eat healthy meals, when the expected response was “most of the time.” In the interview, this woman said, “She [mother] reminds me to take my pills. She reminds me not to eat the food that I'm not supposed to eat.” This PWE has epilepsy and memory difficulties resulting from traumatic brain injury; thus, her condition may have affected her ability to accurately answer the survey questions.

3.5. Differential Item Functioning

We tested whether the items functioned differently for: 1) PWE and PSP and 2) people with probable depression compared to those without. The overall chi-square tests were not significant in either case, indicating that there was no evidence of DIF. Therefore, all of the support for self-management items were ordered in the same way for PWE and PSP, as well as depressed and non-depressed participants.

4. Discussion

The purpose of this study was to examine the patterns of support for self-management behaviors, focusing on the support that PWE receive and that support providers give. Results of the Rasch analysis showed good model-data fit and provided us with a unique way to assess support data.

The variable map provides a valuable visual for comparing people and items. Our results showed good overall overlap, or targeting, between the individuals and items along the logit scale. The overlap indicates that, for the most part, the items appropriately measured the level of support that was received or provided. However, PWE who received the most support (located above 0.6 logits) did not overlap with any items. This suggests that additional unmeasured types of support could be investigated and incorporated into the scale. Results from the qualitative interviews and the differential person functioning also support the addition of items to the scale. For example, the current ERSS does not capture when the support person performs aspects of self-management for the PWE, such as refilling medications, setting medications out for the PWE, and making doctors' appointments.

Results from the qualitative data also indicated that PSP support PWE in ways that are not assessed by the ERSS, such as keeping a record of the PWE's seizures and providing information about the PWE's condition to the doctor. Given these results and limitations of the current ERSS, which measures only nine supports for self-management behaviors, there is a need for further development of the ERSS to incorporate additional self-management tasks and who performs them.

Although relatively few scales measuring support for self-management of chronic diseases are available in the literature, models can be found for diabetes self-management support [31–34]. For example, Naderingaham et al. (2012) developed a scale that includes items assessing how often someone reminds the person with diabetes about specific self-management behaviors, encourages them to complete those behaviors, and completes activities to help the person manage (i.e., buys healthy foods, performs foot care). These scales, however, also illustrate the challenge of comparing results across support scales because they assess different support providers (i.e., someone, family, or family and friends) and different types of self-management support. Some of the measures ask about negatively and positively perceived support, amount of support received, importance of support, and/or satisfaction with support [32–34]. Additionally, the information from the support person was not gathered in any of these instances. Self-management support is a multifaceted concept that can be measured in a variety of ways, resulting in little consistency across studies.

Examinations of the relative ease and difficulty of consistently receiving and providing support for self-management behaviors is also lacking in the literature. We found that the type of support that PWE and PSP reported to receive or provide most often was support for seizures. People with epilepsy almost always wanted their support person to help them when they had seizures. Depending on the type of seizure, PWE can experience loss of consciousness, loss of control over muscle movements, and convulsions. The after-effects of seizures, which can last from less than an hour to over a day, include memory loss, difficulty concentration, fatigue, and headaches. Seizures can be major events that disrupt daily life. Additionally, anticipating and experiencing seizures can cause a great deal of fear and anxiety [35]. Therefore, PWE and PSP may prioritize support for seizures as a way to minimize the physical and emotional consequences of seizures.

Reminders, particularly about taking medication, eating healthy, and getting enough rest, were the most difficult types of support to receive and provide more often; thus participants needed to report a high amount of overall support in order to report often receiving, wanting to receive, or providing reminders. This finding differs from a previous study in which reminders to take medication were the most common type of support reported by PWE who participated in a self-management program [14]. It appears that there is a tension between the ease of simply providing a reminder and the toll that constant reminders can take on both the PWE and PSP. The qualitative data suggest that reminders can be frustrating, especially for PWE who successfully manage their epilepsy own. These results align with findings by DiIorio and colleagues, who found that self-management support was positively associated with anxiety but not associated with medication self-efficacy [23]. The researchers suggested that self-management support could be viewed as nagging or come across negatively [23]. As described by Tapp [36], family members and other PSP may nag out of

concern and as a way to help and encourage a person with a chronic condition. Nagging presents a paradox in that it can be helpful in motivating behavior change or harmful by increasing resentment and irritability between caregivers and care recipients [36]. Additional research is needed to tease out the situations in which nagging is acceptable or harmful for people with epilepsy and their supporters. When designing interventions that include PWE and PSP, these results suggest that intervention approaches, such as motivational interviewing [37], may be helpful in facilitating reflection and conversation about self-management behaviors, support, and responses to support.

The results of the DIF analyses provide additional information about the nuances of support that is received and provided. No DIF was found when comparing PWE versus PSP as well as non-depressed versus participants with elevated depressive symptoms. This means that the items were ordered the same way for the different groups—individuals in both groups had similar perceptions about how often support was received or provided across the items. This suggests that PWE and PSP have similar perceptions of the different types of support. Additionally, it appears that the presence of depressive symptoms was not associated with participants perceiving certain support behaviors as easier or harder to receive or provide more often. Further investigation of the influence of depressive symptoms on support for self-management, particularly related to self-management tasks that could be influenced by mood, is warranted.

4.1. Limitations

While the results of this study are strengthened by the mixed methods design, three main limitations of this study should be considered. First, the sample size is small; therefore the results should be interpreted with caution. While Rasch analyses are often conducted on large samples, the small sample enabled us to examine individual and item characteristics in detail and compare them to the qualitative results. However, replication of the findings in a larger sample would be useful, particularly for the DIF analysis. Second, the sample was drawn from one hospital-based epilepsy clinic; therefore the results may not be generalizable to all PWE and PSP. Only PWE who attended their appointment, and, thus could be referred by clinic providers to study staff, and who had a PSP were included in this study. Therefore, participating PWE may be different from PWE who were unable to attend their appointments or who did not have a support person. These results are most likely to pertain to PWE who have support available. Finally, these analyses are cross-sectional and exploratory; no conclusions about causation can be drawn from the results.

4.2. Conclusions

This research demonstrates how Rasch modeling can provide valuable information on self-management behaviors beyond its traditional use in psychometrics. Rasch analyses would be useful in future research examining the alignment between the amount of support PWE perceive they receive and the amount of support that PSP feel that they provide. Additionally, a revised scale for self-management support could be developed that includes additional behaviors and captures when the support person performs the self-management behaviors.

For PWE and their support persons, the results suggest that not all types of support are equally as easy to consistently receive and provide. Self-management programs for PWE should address these differences and facilitate conversations between PWE and support providers in order to optimally meet PWE's support needs.

Acknowledgments

This study was supported by funding from Emory University's Laney Graduate School (Professional Development Support) and Department of Behavioral Sciences and Health Education (Letz Funds). The funders had no involvement in the study design; collection, analysis, or interpretation of the data; or in the preparation or submission of this paper.

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Logits	Persons (PWE)	Persons (PSP)	Items (Support Received or Provided)	Items (Support PWE would like to receive)	Quotes
	More support received	More support provided	Harder to give/receive more often	Harder for PWE to want to receive more often	
2	•••				
	•				
	•				
	••				
	••				
	••				
1	••	•			
	••	••			
	••	••			
	••••	••			
	••	••••			
	••	••	Reminder – refill medications	Reminder – take medication Reminder – eat healthy Reminder – rest Reminder – refill medications	“So I won’t have to hear her nag, so I be sure to take it.” (PWE, husband) “I make sure he gets to the doctor. I make sure he always has medication refills.” (PSP, mother)
	••••	••••	Reminder – take medication		
	••••	••••	Reminder – clinic visits, Reminder – eat healthy	Reminder – clinic visits, Reminder – be careful	
	••	••••			
0	••••	••••	Reminder – rest, Reminder – be careful		“Well, I try to ensure that she gets proper sleep, proper rest, not to overdo herself, not to worry.” (PSP, husband)
	••••	•	Help – avoid triggers	Help – avoid triggers Help – drive to doctor appointments	
	••	•	Help – drive to doctor appointments		“She actually takes me to the doctor so she could explain one or two things that may have happened...” (PWE, son)
	••	•			
	••	•	Help – seizure	Help – seizure	“Just try to make sure that she’s safe and she’s, you know, try to get her laying down, that she’s not going to get hurt, that type of thing.” (PSP, mother)
-1	•				
-2					
Logits	Less support received	Less support provided	Easier to give/receive more often	Easier for PWE to want to receive more often	
	•=1 PWE	•=1 PSP			

Figure 1. Support for epilepsy self-management variable map

Table 1
Demographic characteristics for people with epilepsy and their primary support persons

	People with epilepsy (n = 53)	Primary support persons (n = 48)
Gender, n (%)		
Female	34 (64.2)	34 (70.8)
Male	19 (35.8)	14 (29.2)
Race, n (%)		
African American	8 (15.1)	7 (14.9)
White	42 (79.2)	36 (76.6)
Other	3 (5.7)	4 (8.5)
Marital status, n (%)		
Married	16 (30.2)	32 (66.7)
Single	32 (60.4)	8 (16.7)
Separated/divorced/widowed	5 (9.4)	8 (16.7)
Education, n (%)		
High school or less	17 (32.0)	14 (29.2)
Some college or currently in college	17 (32.1)	7 (14.6)
College or more	17 (32.1)	24 (50.0)
Other programs (e.g., technical)	2 (3.8)	3 (6.3)
Employment status, n (%)		
Working	17 (32.1)	27 (56.3)
Student	9 (17.0)	2 (4.2)
Retired	1 (1.9)	8 (16.3)
Unemployed	10 (18.9)	4 (8.5)
On disability	13 (24.5)	2 (4.2)
Other	3 (5.7)	5 (10.4)
Depression level, n (%)		
No depression (CES-D score < 16)	32 (60.4)	33 (68.8)
Possible depression (CES-D score ≥ 16)	21 (39.6)	15 (31.3)
Age (years)		
Range	18–59	18–76
Mean (SD)	31.30 (9.80)	48.23 (13.64)
Seizures in the past 4 weeks		
Range	0–364	–
Mean (SD)	13.94 (54.41)	–
Years since epilepsy diagnosis		
Range	.3–39	
Mean (SD)	14.9 (9.53)	

People with epilepsy (n = 53) Primary support persons (n = 48)	
Dyad characteristics (n = 54 relationships)	
Relationship (PWE/PSP), n (%)	
Adult child/parent	29 (53.7)
Spouse or significant other/spouse or significant other	19 (35.2)
Sibling	4 (7.4)
Parent/adult child	1 (1.9)
Friend	1 (1.9)
Living in same household, n (%)	
Yes	43 (79.6)
No	11 (20.4)

Abbreviations: CES-D, Center for Epidemiological Studies Depression Scale; SD, standard deviation.

Table 2
Facets summary statistics from the Rasch analysis of the Epilepsy Regimen-Specific Support Scale

	Measures			Infit		Outfit		Reliability of separation	χ^2 statistic	p-Value	df
	Mean	SD	n	Mean	SD	Mean	SD				
Persons <i>I</i>	.43	.84	101	1.04	.49	1.11	.87	.80	523.8	<.001	100
Items	0	.53	18	1.05	.35	1.11	.45	.97	399.4	<.001	17
Dyad	0	.18	2	1.00	.06	1.11	.00	.97	37.4	<.001	1
Depression	0	.09	2	.98	.13	1.05	.29	.87	7.5	.01	1

I Includes responses of both people with epilepsy and their support persons

Abbreviation: SD, standard deviation; n, number of participants; df, degrees of freedom

Table 3

Mixed methods data to explain misfit in person functioning

Individuals with misfit	Items with standard residuals < -2 or > 2	Observed response ¹	Expected response ²	Comments on survey	Completed an interview	Information from interview
PWE 1	Reminder to take medication	1	4.00	None		• PWE has brain injury that affects memory
	Reminder to eat healthy	1	4.42	None	Y	• Mother takes care of medications and refills
	Help avoid things that cause seizures	1	3.69	None		
PWE 2	Help avoid things that cause seizures	1	4.1	None		• Support person mainly helps by taking her to the doctor, tracking seizures, and providing support during seizures
	Reminder to be careful	1	3.87	None	Y	
PWE 3	Reminder to take medication	3	1.41	When she is visiting brother, he will remind her about her medication		• PWE's support provider lives out of state, mostly provides emotional support
	How often PWE would like to be reminded to take medication	3	1.26		Y	• She visits him about once a year
	How often PWE would like to be reminded to get enough rest	3	1.32	None		
PWE 4	Bring to a doctor's appointment	3	4.83	None		
	How often PWE would like to be brought to a doctor's appointment	3	4.81	None		
	How often PWE would like to be reminded about a doctor's appointments	2	4.59	None	N	
PWE 5	Reminder to refill medications	1	4.56	Mother refills medications	N	
PWE 6	Reminder to refill medications	1	4.06	Does it online automatically		• Her support person is "in charge" of her medication
	How often PWE would like to be reminded to refill medications	1	4.24		Y	

Individuals with misfit	Items with standard residuals <-2 or >2	Observed response ¹	Expected response ²	Comments on survey	Completed an interview	Information from interview
PSP 1	How often the PWE would like help with seizures	1	4.89	None		
	How often the PWE would like to be reminded to be careful	1	4.14	None	N	
PSP 2	Reminder about a doctor's appointment	5	2.14	None		• She refills meds for PWE and takes him to the doctor
	Reminder to refill medications	5	1.69	None	Y	
	How often the PWE would like help with seizures	1	4.36	None		
PSP 3	Help with seizures	1	4.71	PSP has never been present when PWE has had a seizure	N	

¹ Responses given by the participants. Response options: 1 (never), 2 (rarely), 3 (sometimes), 4 (most of the time), 5 (always).

² Expected responses predicted by the Rasch measurement model.

Abbreviations: PWE, person with epilepsy; PSP, primary support person.