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Problems, Needs, and Useful Strategies in Older Adults Self-Managing Epilepsy: Implications for Patient Education and Future Intervention Programs

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Abstract

Objective—The purpose of this study was to determine, in a sample of older adults diagnosed with epilepsy, perceived self-management problems and needs encountered since diagnosis, as well as strategies used to address problems and needs.

Methods—Qualitative description was used. 20 older adults engaged in face-to-face interviews. Interviews were analyzed via content analysis.

Results—Participants reported problems, needs, and strategies in six categories: Information, Physical and Emotional Symptoms, Memory and Concentration, Medications, Commitments, and Relationships.

Conclusion—Participants noted some problems and needs previously documented in the literature, though current results have built upon extant literature to reveal etiologies of and contexts surrounding problems and needs; new findings were also revealed. This knowledge can be used by health care providers in counseling and educating older adults with epilepsy, and can inform formal self-management interventions.

Practice Implications—Determining needs from the patient's perspective is consistent with today's focus on patient-centered care. Current findings have led to an organizing framework for problems and needs of older adults with epilepsy. More research is needed to develop the

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framework so that it can serve as a template for an intervention. In the interim, findings can inform educational practices of those caring for this population.

1. Introduction

Epilepsy affects 65 million people worldwide, and persons age 60 and older are at highest risk for developing new-onset epilepsy [1]; As life expectancy in Western countries lengthens, the number of older adults diagnosed with epilepsy continues to rise [2].

Persons with epilepsy play a major role in the management of their condition and the achievement of epilepsy-associated outcomes [3, 4]. Treatment and care of those with epilepsy must include not only medical interventions, but also preparation for independent management of the disease. Though older adults are most affected by new-onset epilepsy, investigation into their self-management has been neglected; exploration of older adults' self-management experiences, particularly management-related problems and needs, is important in order to develop patient-centered, outcome-enhancing interventions, or to render existing epilepsy self-management interventions more applicable to older adults [5]. In addition, probing of older adults' experiences with the use of strategies they have employed to manage problems would provide helpful information to researchers developing interventions for this population and to providers caring for older adults with epilepsy.

The purpose of this study was to determine, in a sample of older adults diagnosed with epilepsy at or after age 60, perceived self-management problems and needs encountered since diagnosis. Participants were also asked to discuss strategies used to address problems and needs.

Most epilepsy self-management research has involved younger adults. While older adults may share problems and needs with younger adults with epilepsy, it is possible that their experiences may be unique from those of younger adults due to age-related changes in metabolism [6], polypharmacy, decrements in cognitive functioning [7, 8], increased risk for seizure-related injuries [9], and co-morbidities [10]. Pugh and colleagues [11] documented differences in the ways in which epilepsy affects the health status of younger and older adults, noting differences in physical and mental health in the populations. These authors note that the effect of epilepsy on older adults should not be inferred from the younger adult literature [11].

Martin and colleagues [8] published the only report about concerns of older adults with epilepsy. In a sample of 33 older adults with intractable partial epilepsy, investigators found that chief concerns were difficulty with transportation (64%) and anti-epileptic drug (AED) side effects (64%). Other prominent concerns included safety, medication costs, and employment [8].

The Martin and colleagues [8] study provides important insight into some concerns of older adults with epilepsy, although it has limitations. First, the sample included very few adults over 70 years of age and did not focus on those diagnosed after age 60. Further, the sample was comprised only of those with intractable partial epilepsy. Finally, methods used in the study, though appropriate for its purposes, do not provide the deeply analyzed, context-

dependent descriptions of experiences [12] needed to inform patient-centered interventions. Building upon Martin and colleagues' [8] results, an in-depth investigation into older adults' problems and needs regarding epilepsy self-management, as well as the strategies they use to address these problems and needs, is warranted.

2. Methods

Following approval by the Institutional Review Board, a convenience sample was recruited. Inclusion criteria were: (a) diagnosis of epilepsy at or after age 60, (b) diagnosis at least six months prior, (c) prescription of an AED, (d) community-dwelling, and (e) cognitively able to engage in a face-to-face interview, as measured by the Six-Item Screener for Cognitive Impairment [13]. Twenty participants were recruited from a Midwestern private neurology practice and a hospital-based clinic. Detailed recruitment activities are reported elsewhere [14].

After obtaining informed consent, demographic data were collected; participants then took part in a face-to-face interview. Interviews, ranging in length from 40 minutes to two hours, were audio-recorded. The following questions guided the interview:

- 1. What problems have you experienced since being diagnosed with epilepsy?
- 2. What do you feel you need to manage your epilepsy?
- 3. What strategies have you used to deal with the problems and needs you have?
- **4.** Which strategies have you found most helpful, and why? Are there other strategies that might have helped?

Probes were used based on responses [15].

Interviews were transcribed and analyzed via conventional content analysis [16], using interview questions as a framework [17]. Analysis was ongoing throughout and was initiated after the first interview. Recruitment and analysis occurred simultaneously and ceased when informational redundancy occurred.

The authors analyzed the data using Sandelowski's [17] guidelines. A coding scheme was developed and tested against all data; themes emerged [18]. To maintain interpretive validity, an audit trail was kept [19].

3. Results

3.1. Sample

Eight (40%) participants were men, and 12 (60%) were women. Mean age was 70 years, with a range of 60–80. Table 1 shows demographic characteristics.

3.2. Themes

Participants reported problems and needs in six categories: *Information, Physical and Emotional Symptoms, Memory and Concentration, Medications, Commitments, and Relationships* (Table 2). Strategies are reported in Table 3.

3.2.1. Theme One: Information—Most (n=15) indicated problems and needs related to information about epilepsy. They reported that lack of information about the pathophysiology, prognosis, presentation, and treatment of epilepsy was particularly troubling. Only brief information had been given to participants about their condition, and it was often given in terms they found difficult to understand. Participants reported that the lack of information they received from providers began at the time of diagnosis and continued thereafter. One stated, "They said the wiring in my brain misfired...I didn't know what that meant. I didn't...want to seem stupid...but I had no idea." Many found that lack of information led to inability to explain their condition to others, causing embarrassment. In addition, several reported not knowing when to call epilepsy care providers. Many (n = 10) were embarrassed to mention to providers that they did not understand the information given to them.

All participants had at least one co-morbidity, and many (*n*=14) reported needing information about how to self-manage epilepsy in the midst of other conditions. One explained, "The discussion we had when I found out I had [epilepsy] and since... have been about only seizures. I need to know how all these problems affect each other."

<u>3.2.1.1. Strategies:</u> Participants reporting informational needs had addressed these needs by seeking out information (via Internet or books) (n=10), taking notes or using audio recorders during provider visits (n=4), or talking with another person with epilepsy (n=3).

Some found Internet resources helpful, though most found that information online or in books added to their confusion. Several reported lacking skills to search online, while others had unreliable Internet connections. Those who relied on books found them difficult to understand.

All three participants who reported making contact with others with epilepsy and asking questions of them found this strategy helpful. "It helped a lot and we still talk," said one. All participants reporting the use of note-taking or audio recording during visits with their care providers also found these strategies very helpful.

- **3.2.2. Theme Two: Physical and Emotional Symptoms**—Eighteen participants described problems related to physical symptoms associated with epilepsy, including fatigue (n=16), lack of energy (n=14), nausea (n=11), headaches (n=9), insomnia (n=9), and pain (n=7). Fifteen reported problems with emotional symptoms, including depression (n=13), anxiety (n=12), and anger (n=7). They reported that these symptoms had negatively affected their lives. As one explained, "I now am not real able to do what I need to do. I could sit here... and not move. I'm exhausted and depressed."
- <u>3.2.2.1. Strategies:</u> Participants who reported physical and emotional symptoms shared that they had addressed these problems by talking with family, friends, or spiritual advisors (n=7), practicing stress relief exercises (n=5), taking regular naps (n=5), using non-prescription medication (n=5), and speaking to care providers about symptoms (n=2).

Five of seven participants who reported talking to family, friends, or spiritual advisors found this strategy helpful. One explained, "I told my [friend] I didn't know how long I could go on...tired and depressed. She said let's call your doctor...now I have anti-depressants." Two participants, however, did not find the strategy helpful due to it straining these relationships.

All who reported use of stress-relieving activities found them helpful in managing symptoms. One man shared, "I find getting out for a walk every day...gives me energy back." Five reported that they took daily naps, and three found this practice helpful.

Five participants reported using over-the-counter medications to address symptoms, especially insomnia and pain. However, only two found this strategy useful. The remaining participants did not find relief from such medications, and some found them harmful. "I was taking a sleep medicine with [diphenhydramine] in it and apparently that makes you more apt to have seizures...which I did," said one.

Only two participants reported discussing symptoms with care providers. As described earlier, one of these persons found that strategy helpful, and it resulted in her being prescribed anti-depressants. The other participant, though, did not find the strategy fruitful. She explained, "Basically, he said that people...with seizures have anxiety. It's part of it and I have to try to relax."

3.2.3. Theme Three: Memory and Concentration—Thirteen people mentioned having short-term memory problems since diagnosis, and 11 reported problems with concentration. They reported forgetting to take medications, and also misplacing items, missing appointments, and forgetting previous conversations; they found this memory loss very distressing. One explained, "The worst thing has been my memory. I can't keep track of anything.... It makes everything embarrassing." Participants reporting concentration problems found activities like reading or conversations to require extra effort. Further, participants reported needing help keeping track of medication regimens.

<u>3.2.3.1. Strategies:</u> Strategies used to address memory and concentration problems included using a calendar (n=7), relying on others (n=7), setting alarms (n=5), and dividing activities (n=3).

Five who reported utilizing a calendar found the strategy helpful for memory problems. Said one, "I have a to-do list for the next day that I write out ...I put things like 'get the mail' on it ...and then after I do it I cross it off...that tells me I've already done it or I find myself doing things twice."

All who reported relying on others to help them remember things found this to be a useful strategy. "God bless my wife. She keeps track of everything. I just let her take control of... the schedule," explained one man. Four persons, however, indicated that they believed this strategy, though useful, strained the relationship with the person on whom they relied. "It's a burden," shared one.

All who reported setting reminder alarms and dividing activities into sessions found these strategies useful. One explained, "If I decide I need to do something later that day, I have to set an alarm to remember to do it. It helps a lot."

3.2.4. Theme Four: Medications—All participants reported experiencing problems with medications—both AEDs and others. More than half the sample (n = 11) reported difficulty paying for AEDs and/or other medications. Those on Medicare described financial problems when they entered the donut hole—a gap in Medicare coverage—each year. As one explained, "I'm okay until I get to a donut hole. Then I have to dip into savings." Others did not have the luxury of a savings account and either relied on family to help them with costs or simply did not fill prescriptions for AEDs. "Sometimes it's like pay the electric or get my medicine…. I want my lights on," explained one. Participants (n = 10) also explained that costs of medications taken for other conditions often competed with costs of AEDs. Similarly, nine had spouses who also had chronic health problems for which medications were required, causing further financial strain.

All but one participant noted the regular experience of AED side effects, including somnolence (85%), memory problems (65%), fatigue (60%), impaired concentration (55%), dizziness (40%), gastrointestinal upset (30%), and irritability (20%). The majority (n = 17) found somnolence and fatigue most troubling. "I'm an avid reader…but on that medication I fall asleep," explained one.

Because participants had at least one other chronic condition, some (n = 9) had problems stemming from polypharmacy. Complex medication regimens sometimes led to financial problems. Others (n = 7) found that the mixing of medications exacerbated side effects or made them feel unwell. Many (n = 12) reported that their already complex medication regimens were made even more so by the addition of AEDs. As one stated, "It's just one more to keep after.... I take 12 pills a day now."

Twelve participants reported difficulty remembering to take AEDs. Most (n = 9) claimed that they often took AEDs late, and a few (n = 3) reported regularly missing doses. Participants blamed late and missed doses on a decline in memory and the complexity of medication regimens. One man explained, "I can't tell you exactly how many times I've made a mistake, but I know that sometimes I get mixed up about what to take and when."

Others (n=7) described needs related to transportation to pick up medications from the pharmacy. "I do miss my pill sometimes…because we are way out here in the country… we are at the mercy of neighbors to pick things up for us," explained one rural-dwelling woman. Others (n=7) mentioned needs related to organizing and remembering to take medications.

<u>3.2.4.1. Strategies:</u> To manage medication-related problems, participants reported relying on others for help (n=7), tailoring medication schedules (n=7), applying for assistance (n=4), utilizing a social worker (n=4), and altering AED dosages (n=4).

The perceived effectiveness of relying on others for help with medications was mixed. "This container has slots for day and night, and it holds a whole month's worth...some of the meds I take are not every week ...[my daughter] organizes it for me so I don't have to think about

it," explained one man. Another, however, found relying on his wife for assistance with medication organization to be problematic due to causing further confusion. Five participants who relied on others for help with medications reported that they had also relied on family members or friends for financial assistance with medications, and four of these persons found this strategy problematic due to straining of these relationships.

All who reported altering medication schedules in order to facilitate their ability to remember to take them or to reduce side effects found this tactic useful. Explained one, "I had to sit down and simplify it. I now take pills three times a day instead of six or seven."

All participants who utilized financial assistance programs offered by AED manufacturing companies found this strategy helpful. Also, all who had used social workers to assist with obtaining medications found this strategy useful.

Four reported altering AED dosages, both to save money and to avoid side effects. All four found the strategy problematic, if necessary. One explained, "Taking a half dose of my [AED] helps in terms of it's better...than not taking any until I have money. But it's not good."

3.2.5. Theme Five: Commitments—Sixteen participants reported they could no longer keep as many work and volunteer commitments as they could pre-diagnosis. Seven had been working full- or part-time when diagnosed, and six reported having to work fewer hours after onset of epilepsy. Explained one man, "I went from part-time down to *really* part-time." Two found that they could no longer keep their jobs after being diagnosed. Others who no longer worked found that they could not manage as many volunteer activities.

Others (n=4) reported trying to make and keep commitments as they did before being diagnosed with epilepsy, but that doing so was very difficult. "I let a lot of people down on a regular basis," said one. Half (n=8) of participants who reported problems with commitments described a need to restore a sense of purpose in their lives. As one man explained, "I feel useless now. I sometimes feel like I don't have anything to give back."

<u>3.2.5.1. Strategies:</u> Participants reported the use of two strategies regarding commitments. Four reported making a conscious effort to change their expectations, and others (n=4) described a complete withdrawal from pre-epilepsy commitments.

Altering expectations was a helpful strategy for all who used it. "Instead of trying to make everything seem like it was the same...I finally accepted that things are different," one explained. All who reported a complete withdrawal from pre-epilepsy commitments found the strategy to be effective in reducing commitment burdens, though undesirable in other ways. Explained one, "I just could not keep up anymore... I just threw my hands up."

3.2.6. Theme Six: Relationships—The majority (n = 12) reported problems related to undesirable changes in relationships. Alterations and reversals in usual roles were the cause of most problems. For example, many (n = 9) had become more reliant on family members. One explained, "We've been together 40 years... real independent. But now...[my husband] hovers. I went from being wife...to child."

Relationships with friends were altered most by social isolation resulting from the diagnosis. Participants believed that their lack of ability to participate in normal activities had negatively affected their friendships. Others found they felt more comfortable isolating themselves from friends as a consequence of embarrassment and a lack of desire to disclose the diagnosis. One explained, "It was easier to kind of fade out for a while so I wouldn't have to tell anybody."

<u>3.2.6.1. Strategies:</u> Two persons described sharing such problems and needs with those with who they were in relationships. One reported seeking help from a marriage counselor, and one attended an epilepsy support group.

The strategy of discussing relationship-related problems and needs with others was beneficial. One woman said, "Getting it out there in the open, just talking to [my husband] and acknowledging that things are different, that helped ease tension."

One woman reported that she and her husband found marriage counseling helpful. "We knew that our marriage got rocky around [my diagnosis]...we ended up talking and realizing that it was hard for both of us...and we were able to stop resenting." One male said that he found an epilepsy support group to be helpful for dealing with troubled relationships.

4. Discussion and Conclusion

4.1. Discussion

Current findings have important implications for the design of formal self-management interventions for older adults with epilepsy, the tailoring of existing, successful self-management interventions to older adults, and for inpatient and outpatient education offered by health care providers.

Participants in this sample noted problems and needs in six categories (see section 3.2.). Authors of one other published study [8] have examined the concerns of older adults with epilepsy; some of the current findings are similar to those in that study, while others are aberrant. As was seen in the Martin and colleagues [8] study, participants in this sample were chiefly concerned with AED costs and side effects, memory loss, transportation (related to acquiring medications), and employment. However, there are differences in the degree to which the two samples (N=20 in this study; N=33 in the prior study) found some areas concerning. For example, in the prior study [8], only 21% reported memory as a concern, while it was reported by 65% of this sample. This discrepancy may be due to the homogeneity of the sample in Martin and colleagues' [8] study all had partial epilepsy. Participants in this sample were more varied in types of epilepsy, and had been diagnosed at or after age 60. Thus, their memory problems may be more paramount given that they have had less time to adapt.

Findings in this study not reported by Martin and colleagues [8] included problems and needs related to information, physical and emotional symptoms, polypharmacy, maintaining volunteerism, and alterations in relationships due to role reversals. The need for more information about epilepsy has been demonstrated in younger adults [20], though not in

older adults. Of note is that the current finding regarding participants' need for more information about how epilepsy interacts with other chronic conditions is not seen in the younger adult literature. Findings related to problems with physical and emotional symptoms align with findings of qualitative studies involving younger adults with epilepsy [11, 20, 21] and in two quantitative studies involving older adults with epilepsy [11, 20]. A decline in physical functioning is common in persons with chronic diseases [22], and this decline is more pronounced in older adults, especially those with co-morbidities [22, 23].

Participants spoke emphatically about polypharmacy as problematic. Other published studies have not reported on older (or younger) adults' polypharmacy, co-morbidities, or those of their spouses in relation to medication-related concerns. The finding regarding participants' inability to maintain pre-diagnosis levels of volunteer commitments is also unique. No published studies have reported the concern regarding volunteer activities in either younger or older adult populations with epilepsy. Volunteerism is likely of less pertinence to younger adults with epilepsy. The reason for the lack of volunteerism concerns among older adults in the Martin and colleagues [8] study is not clear, though it could be due to the intractable nature of participants' epilepsy, or because participants listed concerns without open-ended questions or probing.

In this sample, role reversals were a key problem, as was social isolation. Decrements in relationships and social isolation have been reported in younger adults with epilepsy [20, 21]. However, the literature does not explicate whether relationship problems experienced by younger adults with epilepsy are due to role reversals.

No published studies have described patient-reported strategies to address epilepsy-related problems and needs in older adults. Strategies shared by this sample depicted in Table 3 showed mixed perceptions of helpfulness. Further research in this area is warranted, particularly when developing interventions.

There are limitations to this study. Only one African American participant was recruited into the study; the remaining 19 were white. Findings thus may not represent experiences of African American or other minority older adults. Also, participants were recruited from one Midwestern state. Though various socioeconomic statuses and levels of education were represented, findings would be strengthened by a more geographically diverse sample. Finally, the majority of the sample were women (60%; n=12). Results may be more representative of experiences of older women than those of older men.

4.2. Conclusion

This study detailed problems, needs, and strategies of older adults with epilepsy, specifically those diagnosed after age 60. Members of this sample noted some problems and needs that have been similarly documented in the younger and older adult epilepsy literature. However, current results have built upon extant literature to reveal not only problems and needs faced by older adults self-managing epilepsy, but also specific etiologies of and contexts surrounding problems and needs; new findings, including strategies used to address problems, were also revealed. This detailed knowledge can be used by health care providers in counseling and educating older adults with epilepsy, and can also inform formal self-

management interventions. The use of context-based knowledge resulting from this study may enhance effectiveness of interventions for this population by ensuring that they are patient-centered.

4.3. Practice Implications

Determining needs from the patient's perspective is consistent with today's focus on patient-centered care [24] and allows for future development of interventions that can empower patients to assess their needs and to seek individualized strategies with the help of health professionals. Current findings have led to an organizing framework for problems and needs of older adults self-managing epilepsy (Table 2). This framework could be used to develop a problems and needs assessment checklist, similar to one developed for stroke caregivers by Bakas and colleagues [25], that would allow older adults to self-identify problematic areas. More research is needed to further develop the framework depicted in Table 2 so that it can be adapted it into an assessment checklist and serve as a template for further intervention development. In the interim, these findings can inform the educational practices of those caring for older adults with epilepsy by making care providers aware of problems, needs, and strategies of pertinence to older adults with epilepsy.

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Highlights

- We examine problems and needs faced by older adults self-managing epilepsy.
- We also examine strategies used to address these problems and needs.
- Participants described six areas in which they face problems and needs.
- Findings provide an assessment framework for problems and needs from the patient's perspective.
- Findings can be used to inform patient-centered intervention development.

Table 1

Demographic Characteristics of Sample. *N*=20.

Variable	M(SD)	Range	N
Age (in years)	70	60-80	
Years since diagnosis	4.1	0.5-10	
Education (years of school completed)	13.5	7–20	
Co-morbidities in addition to epilepsy	2.5	1–4	
Race			
Caucasian			n = 19
African American			n = 1
Gender			
Male			n = 8
Female			n = 12
Income (annual)			
< \$20,000			n = 4
\$21,000-\$40,000			n = 3
\$41,000–\$60,000			<i>n</i> = 6
\$61,000-\$100,000			<i>n</i> = 5
>\$100,000			n = 2
Employment			
Working full-time			n = 2
Working part-time			n = 3
Retired			n = 14
Disability			n = 1
Type of epilepsy			
Tonic clonic			n = 4
Partial with experiences of tonic clonic at times			n = 16
Insurance			
Medicare			n = 17
Private			n = 2
None			n = 1
Relationship status			
Married			n = 14
Single (includes divorced or widowed)			n = 4
Living with significant other			n = 2
Seizure Frequency			
Daily			n = 1
Weekly			n = 2
Monthly			n = 4
Bi-monthly			n = 8
Bi-annually			n = 4

Variable	M(SD)	Range	N
Fewer than one per year			n = 1

Table 2

Categories of Problems and Needs. N=20

Category o	of Problems/Needs	Total Number of Participants Reporting	Percentage
Information	n from providers	n=15	75%
•	Pathophysiology, prognosis, presentation, and treatment		
•	Self-management, especially in the context of other chronic conditions		
•	Delivery of information and format		
•	When to contact care providers		
Physical Sy	rmptoms	n=18	90%
•	Fatigue		
•	Lack of energy		
•	Insomnia		
•	Nausea		
•	Headaches		
•	Pain		
Emotional	Symptoms	n=15	75%
•	Depression		
•	Anxiety		
•	Anger		
Memory		n=13	65%
•	Short term		
Concentrati	ion	n=11	55%
•	Reading/hobbies		
•	Conversations		
Medication	s	n=11	55%
•	Financial issues		
•	Other/spousal medications		
•	Side effects		
•	Missing doses		
•	Transportation		
Commitme	nts	n=16	80%
•	Employment		
•	Volunteerism		
Relationshi	ps	n=12	60%
•	Role alterations/reversal		
	Social isolation		

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Strategies Used by Participants. N=20

Category of Problems/Needs	Strategy	Number of Participants Reporting	Helpful	Not Helpful	Mixed
Information	Seeking information via books, Internet, or other people.	n=13			×
	Having others seek out information.	n=12			×
	Taking notes/recording health care provider interactions.	n=4	×		
	Talking with another person with epilepsy.	n=3	X		
Physical/Emotional Symptoms	Talking with family members, friends, or spiritual advisors.	L=n			×
	Practicing stress relief strategies.	<i>n</i> =5	X		
	Taking scheduled naps.	<i>n</i> =5			×
	Self-medicating with non-prescription medications.	<i>n</i> =5			×
	Talking to epilepsy health care providers.	n=2			×
Memory/Concentration	Using a personal calendar.	L=u			×
	Relying on others.	L=u			×
	Setting reminder alarms.	n=5	X		
	Dividing activities into sessions.	n=3	X		
Medications	Relying on friends and family for help.	L=u			×
	Tailoring medication schedules.	L=u	X		
	Applying for medication expense assistance.	n=4	×		
	Utilizing a social worker.	n=4	X		
	Altering AED dosages.	n=4		×	
Commitments	Changing expectations.	n=4	X		
	Withdrawing from commitments.	n=4			×
Relationships	Talking with friends and family.	n=2	X		
	Seeing a marriage counselor.	n=1	X		
	Attending an epilepsy support group.	n=1	X		