

Research Article

Differences in Epilepsy Self-Management Behaviors among Young and Older Adults

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The purpose of this study is to assess self-management behaviors among adults with epilepsy and explore differences in behaviors among different age groups. People with epilepsy (n=417) responded to an online or paper-based survey that assessed the frequency of conducting epilepsy self-management behaviors. Responses were analyzed by age group (18- 29, 30-49, and 50+). The majority was Caucasian, female, aged 30-39, and had some college or higher. The impact of epilepsy on respondents differed by age group for a number of areas including reports of being bothered by seizures (F(2, 414)=7.23, p=.001), being bothered by work limitations (F(2, 414)=3.78, p=.024), and being bothered by the mental effects of antiepileptic medicine (F(2, 413)=3.20, p=.042). Social support varied by age group with younger respondents reporting more social support than older respondents (F(2, 414)=3.36, p=.035). Younger people with epilepsy (< 30 years) also reported lower conduct of safety, wellness and treatment behaviors than the older age groups. Generally, social support, safety management, and lifestyle behaviors were conducted less frequently by respondents. Acknowledging the variation in self-management behaviors of people with epilepsy by different age groups may contribute to health care system interventions that tailor education to promote self-care and empowerment for shared medical decision-making.

Keywords: Self-management; Adults; Young adults; Epilepsy; Self-care

Introduction

Epilepsy is one of the most common neurological disorders in the world. Epilepsy currently affects an estimated 50 million people globally [1]. It affects people of all ages, races, and ethnic groups [2,3]. People with epilepsy face challenges such as managing complex behaviors, having poor psychosocial adjustment, or experiencing lower quality of life [4-6]. However, self-management helps people with epilepsy to increase their self-efficacy enabling them to better cope with their disease and to lead better quality lives [4,7]. Interventions applying the chronic care model, which encourages active patient engagement in their health care and self-management behaviors, also can reduce health care expenditure and lower utilization of health care services [8].

Epilepsy self-management encompasses “the information and resources that people with epilepsy and their families need to develop skills and behaviors that enable them to actively participate in patient-centered care” (p. 253) [9]. DiIorio further proposes that epilepsy self-management is “the sum of all steps individuals takes to control seizures and the effects of living with a seizure disorder” [4]. Optimal self-management targets two general and distinct areas of self-care: 1) epilepsy-specific management and 2) chronic care management [9]. Epilepsy-centric management includes domains of medication adherence and treatment management, seizure management, safety concerns, seizure triggers, and comorbidities. In contrast, chronic care self-management includes domains of lifestyle management, health care team partnership, and independent living [9]. Self-management has been studied for various chronic diseases such as diabetes and

asthma, yet there is a paucity of knowledge of comprehensive epilepsy self-management. Epilepsy education and care has focused primarily on medical compliance and seizure control [10]. The Living Well with Epilepsy II conference recommended research on self-management of epilepsy, specifically to understand common self-management components and behaviors among people with epilepsy [11]. A 2013 IOM report on the public health dimension of epilepsy has reaffirmed the need for developing and promoting self-management and educational programs [9]. The advent of the CDC PRC Managing Epilepsy Well (MEW) Network has further promoted research on epilepsy self-management [12].

Despite advances in the field, educational interventions to impact epilepsy self-management are still limited [9,11,12] Bradley and Lindsay found few interventions for adults with epilepsy with only 2 focusing on self-management [13]. Helgeson and colleagues evaluated a two-day treatment program (Sepulveda Epilepsy Education (SEE) focused on medication and psychosocial education among adults with epilepsy who were on AEDs. They found that the treatment group reported a significant increase in understanding of epilepsy, decrease in fear of seizures, and a decrease in hazardous medical self-management practices [14]. The MOSES program, a two day group-based education on various topics, resulted in increased epilepsy knowledge and coping with epilepsy [15]. Finally, a more recent online, self-management intervention found that the treatment group had higher levels of medication adherence than the control group at 12 weeks and increased self-efficacy for managing medicines, stress and sleep among program completers [16].

Table 1: Descriptive statistics of participants by age group, % (n).

	Less than 30	30 - 49	50+	Total
Total Population (n=417)	22.3% (93)	47.7% (199)	30.0% (125)	100.0% (417)
Gender (n = 415)**				
Female	78.5% (73)	76.8% (152)	61.3% (124)	72.5% (301)
Male	21.5% (20)	23.2% (46)	38.7% (48)	27.5% (114)
Race/Ethnicity (n = 417)				
White	80.6% (75)	81.9% (163)	87.2% (109)	83.2% (347)
Black	6.5% (6)	10.1% (20)	4.8% (6)	7.7% (32)
Other	12.9% (12)	8.0% (16)	8.0% (10)	9.1% (38)
Education (n = 415)*				
Less than high school	7.5% (7)	5.1% (10)	0.8% (1)	4.3% (18)
High school	15.1% (14)	16.2% (32)	12.9% (16)	14.9% (62)
Some college	46.2% (43)	33.8% (67)	37.1% (46)	37.6% (156)
College or higher	31.2% (29)	44.9% (29)	49.2% (61)	43.1% (179)
Income (n = 361)				
Less than 20k	43.5% (30)	26.4% (47)	27.2% (31)	29.9% (108)
20k to 50k	26.1% (18)	29.8% (53)	27.2% (31)	28.3% (102)
Above 50k	30.4% (21)	43.8% (78)	45.6% (52)	41.8% (151)

*p < .001, ** p < .005* p < 0.05

Relatively few educational interventions on coping and self-management for children and young adults with epilepsy exist [16,17] and many of these studies have less rigorous study designs or accrue small numbers [18-20]. Nevertheless, a few studies have found that educational interventions for children and adolescents increase knowledge and self-efficacy for seizure management and reduced emergency room visits and school absenteeism among children with epilepsy [21,22]. Additional research is needed to develop self-management models across the spectrum of skills required to manage epilepsy and its treatment and to activate patients in order to increase their daily functioning.

This study contributes to the understanding of self-management among adults across a spectrum of ages. The purpose of this study is to assess self-management behaviors among adults with epilepsy and explore differences in behaviors among different age groups. Knowledge of the differences and commonalities in key areas of self-management by age groups of adults with epilepsy can assist clinical intervention, services and programs to better tailor education and tools for them and their families.

Materials and Methods

Data collection on a self-management instrument occurred from October 2013 to February 2014 [23]. This cross-sectional study is a subset analysis of the testing of an adult self-management instrument. The Emory Institutional Review Board approved the study procedures. Further IRB reviews of the study protocol were conducted at all of the non-Emory clinical sites, the Professional Advisory Boards of the Epilepsy Foundation and the Epilepsy Foundation of Metropolitan New York.

Participants were recruited through multiple channels, including through online websites and epilepsy centers. Online recruitment

involved postings on Research Match, postings on social media (Facebook and Twitter) and various websites [e.g., the MEW Network web-site]. Other advertisements included the Epilepsy Therapy Project electronic newsletter and an announcement on UCB pharmaceutical's Facebook wall. For clinic-based recruitment, adult patients with epilepsy seen at epilepsy centers or clinics were invited to participate and were provided with a survey with a stamped, return envelope. The clinical recruitment sites occurred in 6 states: Georgia, Michigan, New York, Ohio, Rhode Island, and Texas.

To be included in the study, participants were: 1) at least three months post diagnosis of epilepsy; 3) 18 years of age or older; 4) residents of the United States; 5) able to read and write in English.

Instrument

The Epilepsy Self-Management Instrument measured the frequency of engaging in self-management behaviors. The instrument was developed by a workgroup sponsored by the MEW Network through phases of item generation and content validity testing (see Escoffery et al. for details of the instrument development) [24]. The final self-management instrument included 113 items organized in 10 exploratory domains for epilepsy self-management. The workgroup expanded self-management beyond medication adherence, safety and seizure control to include behaviors and tasks necessary to manage health care, social relations, coping skills and information management [25-29]. The exploratory domains included: treatment, symptom, seizure, lifestyle, wellness, safety, information, communication, social support and stigma management. Each of scale item was rated on a 5-point Likert scale (i.e., 1=never to 5=always, 1=none to 5=all of the time, 1=not at all to 5=completely true). Participants could also indicate that behaviors were "Not applicable". Higher total scores indicated greater frequency of conducting the self-management behavior. Nine items were negatively phrased and scores were

Table 2: Epilepsy History of Participants by Age Group.

	Less than 30	30 - 49	50+	Total
Time with Epilepsy, years (n=400)***				
Mean (SD)	10.96 (6.72)	19.07 (11.79)	29.78 (18.35)	20.62 (15.02)
Range	0.58 - 28	0.25 - 46	0.75 - 64	0.25 - 64
Had a Seizure in Last 12 months (n=417)*	76.30%	81.90%	72.80%	77.90%
Type of Seizure (n=417)				
Simple partial	33.3% (31)	33.7% (67)	36.0% (45)	34.3% (143)
Complex partial	37.6% (35)	50.3% (100)	42.4% (53)	45.1% (188)
Partial with progression to secondarily generalized	18.3% (17)	22.6% (45)	13.6% (17)	18.9% (79)
Absence	37.6% (35)	32.2% (64)	28.8% (36)	32.4% (135)
Tonic-clonic*	58.1% (54)	55.3% (110)	40.0% (50)	51.3% (214)
Atonic	7.5% (7)	3.4% (14)	1.4% (6)	6.5% (27)
Other primary generalized type	16.1% (15)	14.6% (29)	10.4% (13)	13.7% (57)
Total Types of Seizures Reported (n=395)				
1 type*	35.3% (30)	38.6% (73)	52.9% (64)	42.3% (167)
2 types	28.2% (24)	25.9% (49)	28.9% (35)	27.3% (108)
3 types	16.5% (14)	19.0% (36)	9.9% (12)	15.7% (62)
4 types or more	20.0% (17)	16.4% (31)	0.083 (10)	14.7% (58)
Current Treatment (n=417)				
Seizure medicines	92.5% (86)	96.0% (191)	96.8% (121)	95.4% (398)
Epilepsy surgery	3.2% (3)	2.0% (4)	3.2% (4)	2.6% (11)
Device	12.9% (12)	10.6% (21)	8.0% (10)	10.3% (43)
Dietary treatment	2.2% (2)	4.5% (9)	3.2% (4)	3.6% (15)
None	5.4% (5)	2.0% (4)	2.4% (3)	2.9% (12)
Other	9.7% (9)	4.3% (18)	1.4% (6)	7.9% (33)
Seizure Severity score (n=407)				
Mean (SD)	20.26 (4.09)	20.87 (4.56)	19.96 (4.17)	20.46 (4.35)
Range	30-Nov	31-Oct	Nov-33	Oct-33
Total Medicines Prescribed (n=414)				
Mean (SD)	4.53 (3.83)	5.80 (4.74)	5.98 (5.24)	5.57 (4.74)
Range	0 - 20	0 - 35	0 - 40	0 - 40
Provider Seen (n=417)				
Primary care provider	23.7% (22)	20.6% (41)	23.3% (29)	22.1% (92)
General neurologist	61.3% (57)	58.3% (116)	56.0% (70)	58.3% (243)
Epileptologists	46.2% (43)	44.2% (88)	48.0% (60)	45.8% (191)
Other epilepsy specialist	16.1% (15)	11.1% (22)	8.8% (11)	11.5% (48)
Mental health professional	5.4% (5)	9.0% (18)	5.6% (7)	7.2% (30)
Visited Neurologist in Past Year (n=417)	90.3% (84)	89.4% (178)	88.8% (111)	89.4% (373)
Has Other Chronic Condition (n=417)*	40.9% (38)	50.8% (101)	64.8% (81)	52.8% (220)
Health Status (n=415)				
Excellent	10.8% (10)	5.1% (10)	14.4% (18)	9.1% (38)
Very good	33.3% (31)	27.8% (55)	23.2% (29)	27.6% (115)
Good	25.8% (24)	39.9% (79)	30.4% (38)	33.9% (141)
Fair	26.9% (25)	21.7% (43)	2.4% (30)	23.6% (98)
Poor	3.2% (3)	5.1% (10)	8.0% (10)	5.5% (23)

Quality of Life (n=415)				
Very well	16.1% (15)	7.5% (15)	1.2% (15)	10.8% (45)
Pretty well	31.2% (29)	26.6% (53)	27.2% (34)	27.8% (116)
Good	26.9% (25)	34.7% (69)	23.2% (29)	29.5% (123)
Bad parts about equal	18.3% (17)	22.1% (44)	24.8% (31)	22.1%(92)
Pretty bad/ Very bad	6.5% (6)	8.5% (17)	12.8% (16)	9.4% (39)
Little Interest (n=411)				
Not at all	52.7% (49)	37.2% (74)	39.2% (49)	41.2% (172)
Several days	24.7% (23)	33.2% (66)	28.0% (35)	29.7% (124)
More than half the days	15.1% (14)	14.6% (29)	14.4% (18)	14.6% (61)
Nearly every day	5.4% (5)	13.6% (27)	17.6% (22)	12.9% (54)
Feeling Down, Depressed, Hopeless (n=406)				
Not at all	48.4% (45)	35.2% (70)	37.6% (47)	38.8% (162)
Several days	29.0% (27)	33.2% (66)	3.2% (40)	31.9% (133)
More than half the days	8.6% (8)	10.1% (20)	8.8% (11)	9.4% (39)
Nearly every day	11.8% (11)	18.6% (37)	19.2% (24)	17.3% (72)
Epilepsy Effects Bothersome, Mean (SD) (n=417)				
Seizures**	3.62 (1.41)	3.64 (1.39)	3.06 (1.47)	3.46 (1.44)
Memory difficulties	3.37 (1.44)	3.76 (1.29)	3.69 (1.28)	3.65 (1.33)
Work limitations*	2.69 (1.52)	3.21 (1.57)	3.17 (1.62)	3.08 (1.58)
Social limitations	2.58 (1.44)	2.80 (1.44)	2.79 (1.52)	2.75 (1.46)
Physical effects of antiepileptic medication	2.47 (1.36)	2.89 (1.39)	2.82 (1.47)	2.78 (1.41)
Mental effects of antiepileptic medication*	2.71 (1.46)	3.13 (1.40)	2.86 (1.43)	2.95 (1.43)

***p < .001, ** p < .005, * p < 0.05

subsequently recoded in a reverse order in the final dataset, in order to coincide with the frequency rating of the other items.

We also collected demographic characteristic, including gender, age, race and ethnicity, marital status, educational attainment, employment status, insurance, and income. Online survey participants were asked to describe their last seizure by narrative for screening purposes. Information about epilepsy (e.g., years with epilepsy, type, treatment/medication, type of provider seen) and seizures (e.g., recent seizure activity, seizure severity) was assessed. Participants also rated their health status, their quality of life and the effects of seizures on life domains.

Procedure

Eligible adults read through the informed consent and completed the online or paper-based survey. Participants all were mailed or emailed a \$5 gift certificate for completion of the survey.

Analyses

Online survey participants completed the data collection directly into a HIPAA-compliant data collection system. Research staff manually entered paper survey responses (n=42) from the clinics into the data collection system. All paper survey data were checked for accuracy after the initial data entry by another research staff. Online submissions were reviewed for inclusion according to the study eligibility criteria. Participants who did not meet one of the eligibility criteria but proceeded to submit a survey were identified and their

data were excluded. In addition, surveys were omitted if they had duplicate entries or were suspected of fraudulent data. We report on 417 respondents (89 removed and 5 had missing data on age).

Data were imported into SPSS version 22.0 for data analyses [30]. All of the analyses were examined by age group (18- 29, 30 -49, and 50+). Descriptive statistics of demographic characteristics and epilepsy history were calculated with frequencies, mean values and standard deviations. Self-management items were grouped into the a priori domains and composite scores were computed by summing relevant items. A total self-management score was calculated by summation of the 10 domains. Where appropriate one-way ANOVAs were used to test the statistical significance of mean differences between age groups and χ^2 tests were used to test the statistical significance of the categorical differences between age groups. P values of <0.05 were considered statistically significant for the main effect.

Results and Discussion

The range of age of respondents was 18 to 89. About half of the sample was between the ages of 30 and 49 (47.7%), followed by respondents 50 and older (30.0%) and respondents age 30 or younger (22.3%) (Table 1). The majority of the overall sample was Caucasian (83.2%), female (72.5%) and had some college or a college degree or higher (80.7%).

A higher proportion ($\chi^2 = 11.3$, $p = .004$) of respondents were female for the younger than 30 age group (78.5%) and the 30 to 49 age group (76.8%) compared with the 50 and older age group (61.3%).

Table 3: Domain-specific Self-Management Behaviors by Age Groups.

	N	Communication					Information					Lifestyle				
		Mean	SD	95% CI		Sign.	Mean	SD	95% CI		Sign.	Mean	SD	95% CI		Sign.
				Upper	Lower				Upper	Lower					Upper	
Less than 30	93	3.77	0.82	3.60	3.94	.114 <i>n</i> ² =.010	3.63	0.70	3.49	3.77	.757 <i>n</i> ² =.001	3.67	0.62	3.55	3.80	.217 <i>n</i> ² =.007
30- 49	199	3.70	0.83	3.59	3.82		3.67	0.56	3.59	3.74		3.55	0.60	3.46	3.63	
50+	125	3.55	0.84	3.40	3.70		3.62	0.57	3.52	3.72		3.55	0.64	3.44	3.66	
		Safety					Seizure					Social Support				
Less than 30	93	3.04	0.60	2.92	3.17	.682 <i>n</i> ² =.002	3.59	0.76	3.43	3.74	.235 <i>n</i> ² =.005	3.09	0.97	2.89	3.29	.036 <i>n</i> ² =.016
30- 49	199	3.09	0.52	3.02	3.17		3.61	0.67	3.52	3.71		2.90	0.87	2.78	3.02	
50+	125	3.10	0.54	3.01	3.20		3.49	0.75	3.36	3.62		2.76	0.93	2.60	2.93	
		Stigma					Symptom					Treatment				
Less than 30	93	3.95	0.77	3.79	4.11	.248 <i>n</i> ² =.007	3.87	0.91	3.68	4.06	.830 <i>n</i> ² =.001	4.35	0.48	4.25	4.45	.069 <i>n</i> ² =.013
30- 49	199	3.86	0.73	3.75	3.96		3.87	0.91	3.74	4.00		4.35	0.48	4.29	4.42	
50+	125	4.00	0.76	3.86	4.13		3.81	0.96	3.64	3.98		4.46	0.33	4.40	4.52	
		Wellness					Overall									
Less than 30	93	3.79	0.48	3.69	3.89	.196 <i>n</i> ² =.008	3.71	0.50	3.61	3.81	.953 <i>n</i> ² =.000					
30 - 49	199	3.81	0.52	3.74	3.89		3.69	0.44	3.63	3.75						
50+	125	3.90	0.46	3.82	3.98		3.70	0.42	3.63	3.77						

Education was significantly different among the age groups ($\chi^2 = 13.4$, $p = 0.37$). Having some college education was more common among those younger than 30 (46.2%) compared with the 30 to 49 age group (33.8%) and the 50 and older age group (37.1%). However, having a college or higher education was more common among the 30 to 49 age group (44.9%) and the 50 and older age group (49.2%) compared with the younger than 30 age group (31.2%). No other demographic variables were significantly different by age group.

Epilepsy Characteristics

The average length of time with epilepsy for the adults was 20.62 (SD=15.02) with a range of 4 months to 64 years. As expected, the length of time with epilepsy increased with each age group ($F(2, 400) = 52.37$, $p = .000$). For those ages 30 or younger, the mean length of time with epilepsy was 10.96 years. The mean length of time with epilepsy was 19.07 and 29.78 for those between 30 and 49 and 50 and older, respectively. The most common epilepsy types were tonic-clonic, complex partial, simple partial, and absence (Table 2). Many had only 1 seizure type and almost all (95%) were on medication. About 89% had visited a neurologist in the past year, and the most commonly seen providers were neurologists and epileptologists.

Having a seizure in the past year ($\chi^2 = 14.45$, $p = .017$) and reports of tonic-clonic seizures ($\chi^2 = 9.35$, $p = .009$) differed by age group. Significantly more respondents between the ages of 30 and 49 reported having a seizure within the last 12 months (81.9%) compared with respondents 50 and older (72.8%) and less than 30 (76.3%). Significantly fewer 50 and older respondents reported tonic-clonic seizures (40.0%) compared with respondents between the ages 30 and 49 (55.3%) and younger than 30 (58.1%). No other differences by age group were identified for types of seizure. However, significantly more respondents 50 and older reported only one seizure type (52.9%) compared with respondents between the ages 30 and 49 (38.6%) and younger than 30 (35.3%) ($\chi^2 = 14.45$, $p = 0.25$).

As expected, the total number of medications prescribed for

seizures since diagnosis with epilepsy was greater for respondents older than 50 (Mean = 5.98) and between the ages of 30 and 49 (Mean = 5.80) compared with respondents younger than 30 (Mean = 4.53) ($F(2, 411) = 2.94$, $p = .054$). Similarly, the number of respondents with chronic diseases also increased by age group ($\chi^2 = 12.93$, $p = .012$). The proportion of respondents younger than 30 (40.9%) who reported at least one other chronic disease was significantly lower than respondents between the ages of 30 to 49 (59.8%) and older than 50 (64.8%).

The impact of epilepsy on respondents differed by age group for a number of areas. Respondents 50 and older had significantly lower reports of being bothered by seizures (Mean = 3.06) compared with respondents between ages 30 and 49 (3.64) and younger than 30 (Mean = 3.62) ($F(2, 414) = 7.23$, $p = .001$). Respondents younger than 30 had lower reports of being bothered by memory difficulties (Mean = 3.37) compared with respondents between the ages of 30 and 49 (Mean = 3.76) and older than 50 (Mean = 3.69) ($F(2, 414) = 2.94$, $p = .054$). Similarly, being bothered by work limitations was significantly lower for respondents younger than age 30 (Mean = 2.69) compared with respondents between the ages of 30 and 49 (Mean = 3.21) and older than 50 (Mean = 3.17) ($F(2, 414) = 3.78$, $p = .024$). Being bothered by the physical effects of antiepileptic medicine was lower for respondents younger than 30 (Mean = 2.47) compared with respondents between the ages of 30 and 49 (Mean = 2.89) and older than 50 (Mean = 2.82) ($F(2, 412) = 2.92$, $p = .055$). However, the mental effects of antiepileptic medicine impacted respondents between the ages of 30 and 49 (Mean = 3.13) more than respondents younger than 30 (Mean = 2.71) and older than 50 (Mean = 2.86) ($F(2, 413) = 3.20$, $p = .042$).

Self-Management Domains

Differences among self-management behavioral domains by age group were explored (Table 3). An Analysis of Variance (ANOVA) on the domain scores yielded significant variation by age for social

Table 4: Descriptive Statistics for Each Item by Age Group Mean (Standard Deviation).

Item	Less than 30	30 - 49	50+
I do the different tasks needed to manage my epilepsy/seizures	3.85 (1.00)	3.76 (1.14)	3.88 (1.28)
I have healthy ways to solve problems related to my epilepsy/seizures	3.48 (1.16)	3.40 (1.22)	3.55 (1.19)
I work with my healthcare team on plans to manage my epilepsy/seizures	4.2 (1.07)	4.07 (1.18)	4.01 (1.31)
I have ways to remember things that I have to do	3.69 (1.13)	3.66 (0.98)	3.72 (1.09)
I keep healthcare provider or clinic appointments	4.60 (0.75)	4.73 (0.63)	4.79 (0.46)
I have blood tests or other tests done when ordered by my healthcare provider	4.81 (0.57)	4.77 (0.62)	4.84 (0.44)
I set treatment goals with my healthcare provider on how to manage my epilepsy/seizures	3.41 (1.42)	3.30 (1.46)	3.38 (1.43)
I talk about my epilepsy treatment (such as medicine, diet, device or surgery) with my health care provider	4.41 (0.9)	4.39 (1.08)	4.43 (0.96)
I take my seizure medicine the way my healthcare provider prescribes it	4.76 (0.59)	4.69 (0.62)	4.78 (0.65)
I have a way to remind myself to take my seizure medicine	3.96 (1.33)	4.13 (1.21)	4.26 (1.28)
I keep track of the side-effects of my seizure medicine	3.69 (1.32)	3.87 (1.23)	3.88 (1.41)
When my seizure medicine is running out, I take less medicine each day	4.64 (0.82)	4.68 (0.72)	4.76 (0.61)
When my seizure medicine is running out, I spread out the time between doses	4.58 (0.84)	4.58 (0.91)	4.75 (0.61)
Before my seizure medicine runs out, I get it refilled	4.67 (0.70)	4.65 (0.76)	4.81 (0.46)
When my seizure medicine is running out, I stop taking it	4.84 (0.48)	4.80 (0.66)	4.87 (0.59)
When my medicine is running out, I take more of another seizure medicine	4.87 (0.44)	4.89 (0.45)	4.82 (0.68)
I take my seizure medicine at about the same time each day	4.26 (0.86)	4.37 (0.86)	4.67 (0.51)
I forget to take doses of my seizure medicine	4.07 (0.96)	4.05 (0.95)	4.26 (0.87)
I skip doses of seizure medicine without checking with my healthcare provider	4.58 (0.84)	4.53 (0.88)	4.71 (0.74)
I bring my seizure medicine with me when I go away from home	4.74 (0.63)	4.73 (0.81)	4.81 (0.57)
I plan ahead so that I do not run out of my seizure medicine	4.47 (0.86)	4.52 (0.88)	4.77 (0.48)
I put off having my seizure medicine refilled	4.68 (0.76)	4.72 (0.70)	4.83 (0.53)
I check with my doctor, nurse or pharmacist before taking other medicines	4.09 (1.23)	4.19 (1.16)	4.28 (1.07)
I take my seizure medicine the same way every day	4.52 (0.72)	4.48 (0.76)	4.63 (0.65)
I take my seizure medicine as prescribed even on holidays, birthdays, vacations and other special occasions	4.75 (0.74)	4.74 (0.68)	4.91 (0.27)
I do what my healthcare provider instructs me to do when I miss a dose of my seizure medicine,	4.56 (0.72)	4.52 (0.85)	4.61 (0.68)
I keep track of how often I have seizures	4.24 (1.09)	4.17 (1.14)	4.07 (1.30)
I keep track of when my seizures occur	3.85 (1.35)	3.87 (1.26)	3.81 (1.47)
I keep a record of the types of seizures I have	4.05 (1.24)	4.02 (1.27)	3.93 (1.44)
I recognize situations that might cause seizures	3.88 (1.32)	3.98 (1.08)	3.8 (1.20)
I avoid situations or things that might cause seizures	3.82 (1.13)	3.92 (1.07)	4.00 (1.11)
I use/I have used non-medical techniques in addition to my treatment to keep myself from having seizures	2.19 (1.36)	2.37 (1.45)	2.25 (1.35)
I do things such as relaxation or breathing exercises to keep myself from having seizures or to stop them	2.72 (1.48)	2.73 (1.35)	2.37 (1.24)
I call my health care provider if I am having more or different seizures than usual	3.93 (1.16)	3.84 (1.34)	3.71 (1.39)
I tell my health care provider when I think I am having side-effects from my seizure medicine	4.05 (1.21)	4.18 (1.11)	4.13 (1.19)
I tell my health care provider when I think I am having side-effects from my seizure treatment (such a VNS device or diet)	4.18 (0.98)	4.01 (1.12)	3.95 (1.06)
I talk to my health care team if I am too tired or sleepy during the day	2.74 (1.44)	2.88 (1.51)	2.83 (1.46)
I talk to my health care provider if my seizure medicine causes physical problems (for example, changes in weight, upset stomach, feeling shaky, off-balance, or tired)	4.27 (0.99)	4.1 (1.20)	4.11 (1.25)
I talk to my health care provider if my seizure medicine affects my emotions or the way I act (feeling depressed, anxious, irritable or edgy)	4.01 (1.17)	4.04 (1.18)	3.91 (1.28)
I talk to my health care provider if my seizure medicine affects my memory, my attention and my ability to think	3.89 (1.29)	3.93 (1.18)	3.78 (1.29)
I tell my healthcare provider if I have problems with my sleep	3.95 (1.24)	3.94 (1.33)	3.95 (1.29)
I stay informed about what treatments I need or are available to me	3.75 (1.30)	3.79 (1.25)	3.75 (1.32)
I keep up-to-date on information to help me manage my epilepsy/seizures	3.57 (1.4)	3.90 (1.04)	3.87 (1.19)

Item	Less than 30	30 - 49	50+
I use the correct name(s) for my seizure type(s)	4.13 (1.22)	4.21 (1.14)	4.28 (1.12)
I can describe accurately my seizures	3.65 (1.37)	3.50 (1.26)	3.58 (1.39)
I talk with my health care provider about how alcohol affects my seizure control	3.27 (1.23)	3.27 (1.16)	3.09 (1.15)
I talk with my health care provider about how smoking affects my seizure control	2.31 (0.99)	2.27 (0.88)	2.08 (0.61)
I talk with my health care provider about how illicit or recreational drug use affects my seizure control	2.98 (1.22)	3.03 (1.17)	2.82 (1.10)
I can name my seizure medicine	4.72 (0.69)	4.76 (0.61)	4.60 (0.96)
I bring an up-to-date list of all my medicine to healthcare provider's appointments	4.28 (1.2)	4.27 (1.23)	4.49 (1.04)
I take steps to stay safe when I have a seizure	3.97 (1.11)	4.08 (1.08)	4.06 (1.22)
I go swimming alone	4.22 (1.17)	4.29 (1.05)	4.24 (1.13)
I wear or carry information stating that I have epilepsy or seizures	2.91 (1.76)	2.91 (1.8)	2.85 (1.88)
I take showers instead of baths	4.33 (1.06)	4.41 (1.03)	4.39 (1.10)
I wear head protection (such as a helmet) when I play sports such as riding a bike, skating or skiing	2.90 (1.37)	2.63 (1.37)	2.73 (1.27)
I carry a cell phone with me to call someone if I need help	4.83 (0.44)	4.67 (0.76)	4.25 (1.23)
I keep the water temperature in my home low enough so that it would not burn me if I have a seizure in the shower	2.98 (1.65)	2.99 (1.65)	3.08 (1.68)
I don't keep open flames or lighted material (such as candles, space heaters, cigarettes) when I am alone	3.31 (1.45)	3.31 (1.47)	3.67 (1.43)
I use an iron with automatic shut off	2.45 (1.33)	2.90 (1.46)	2.85 (1.53)
I climb on high stools, chairs, or ladders when I need to reach something	2.74 (1.28)	2.72 (1.38)	2.80 (1.44)
I lie down or sit down when I know that I am going to have a seizure	3.63 (1.30)	4.07 (1.05)	3.84 (1.11)
I keep the bathroom door unlocked at home when I am using it	3.72 (1.54)	4.09 (1.40)	4.11 (1.45)
I keep a lid over my cup when I drink a hot liquid	1.92 (1.29)	2.00 (1.33)	1.66 (1.10)
I use power tools such as electric saws, hedge trimmers, or knives, with an automatic shut off	2.3 (1.01)	2.57 (1.16)	2.86 (1.25)
I use safety precautions if I take a shower	2.34 (1.64)	2.35 (1.49)	2.44 (1.57)
I avoid having glass furniture in my home	2.90 (1.52)	2.90 (1.49)	2.89 (1.52)
I use safety precautions when I cook	3.13 (1.49)	3.03 (1.50)	3.14 (1.51)
I have carpet or rugs with thick padding on the floor where I live	2.55 (1.41)	2.61 (1.43)	2.74 (1.42)
I have padding on the sharp edges of the furniture in my home	1.59 (1.11)	1.42 (0.89)	1.55 (1.04)
I make sure that my space heater is secure when I use it	3.18 (1.01)	3.22 (0.93)	3.19 (0.99)
I have seizure drills with my family and friends so that they know what to do when I have a seizure	1.97 (1.3)	1.84 (1.24)	1.82 (1.11)
I talk about how I take my seizure medicine with my health care provider	4.34 (1.03)	4.29 (1.09)	4.28 (1.08)
I talk to my health care provider about my emotions	3.13 (1.43)	3.28 (1.33)	3.32 (1.41)
I talk with my healthcare provider about the long-term effects of my epilepsy treatment	3.70 (1.32)	3.40 (1.39)	3.42 (1.42)
I talk with my healthcare provider about my sleep habits	3.70 (1.28)	3.60 (1.40)	3.54 (1.38)
I have ways to get help if I have a seizure	4.00 (1.18)	3.84 (1.13)	3.62 (1.32)
I teach others not to put something in my mouth when I have a seizure	3.88 (1.46)	4.04 (1.40)	3.63 (1.56)
I teach my family and friends what to do during a seizure	3.64 (1.32)	3.46 (1.37)	3.02 (1.45)
I set long-term goals for my life	3.82 (1.25)	3.58 (1.32)	3.22 (1.43)
I arrange for transportation to get to my appointments	3.72 (1.47)	3.65 (1.38)	3.65 (1.41)
I plan my seizure medicine schedule around things that I do every day	3.72 (1.38)	3.59 (1.55)	3.83 (1.56)
I can take my seizure medicine when I am away from home	4.84 (0.49)	4.77 (0.70)	4.92 (0.26)
I do things that I enjoy to help manage stress	3.92 (1.06)	3.67 (1.07)	3.71 (1.06)
I keep from being discouraged when nothing I do seems to make a difference	3.29 (1.05)	3.13 (1.04)	3.04 (1.14)
I do things that I enjoy with my family and friends despite my epilepsy/seizures	4.38 (0.70)	4.18 (0.85)	4.15 (0.93)
I use some techniques (such as relaxation, guided imagery, and self-hypnosis) to manage stress	2.84 (1.43)	2.87 (1.40)	2.65 (1.44)

support ($F(2, 414) = 3.36, p = .035$) and approached significance for treatment management ($F(2, 414) = 2.69, p = .069$). The mean domain score for social support decreased as the age groups increased, so respondents younger than 30 (Mean = 3.09) and between 30 and 49 (Mean = 2.90) reported more social support than respondents 50 and older (Mean = 2.76). Conversely, respondents 50 and older (Mean = 4.46) reported higher levels of treatment management compared with respondents between the ages of 30 and 49 (Mean = 3.35) and respondents younger than 30 (Mean = 3.35). Social support, safety management, and lifestyle behaviors were conducted less frequently by respondents overall. The overall self-management score was not significantly different by age group (Table 4).

Discussion

To our knowledge, this is the first study examining dimensions of self-management across different age groups. Overall, adults are performing self-management behaviors some of the time to most all of the time. There is still room in our sample for improvement particularly in the area of acquiring social support, safety, lifestyle and seizure management. Younger people with epilepsy (< 30 years) reported lower conduct of safety, wellness and treatment behaviors than the older age groups. This suggests that further intervention is needed to help young people with epilepsy assume responsibility for their care [31], especially since many patients with childhood onset epilepsy have poor social adjustment and experience more educational and occupational problems [32,33]. Healthcare providers can counsel young PWE on the importance of managing their treatment and how to protect their safety in the event of seizures.

For older people with epilepsy in this study, they reported more burden of epilepsy on work limitations, physical health, and mental capacities. It would be helpful for healthcare providers or care teams to ask about these areas as people with epilepsy age during health visits and offer or refer to necessary supports. For example, suggestions for how to communicate with supervisors about their impact of their chronic condition or how to get support through employee assistance programs may be offered. In relation to finding of decreased support for those people who are older (50+), they could be reminded to ask for more assistance from caregivers or others or attend support groups to learn how to cope with daily living with epilepsy.

Although self-management behaviors related to medication and treatment are important, many people with epilepsy desire additional information [9]. Researchers have identified needs around safety and injury prevention, social and psychological problems, comorbidities, healthy lifestyles and social and community resources [33,34]. This study validated these same needs in that participants reported less frequent conduct of these types of self-management behaviors. To meet the standard of the Chronic Care Model of a patient-centered approach [35,36], epilepsy programs and services should help people with epilepsy become more efficacious and competent in self-management, communicating with providers and partnering in health care decision making and accessing resources to meet their needs [37]. Consequently, people with epilepsy will be better educated about their condition and feel more confident dealing with their disease on a daily basis [38]. This should be a priority for future education and intervention.

Epilepsy self-management means that patients actively

participate in their health care [5,39-41]. It is important to assess tasks and behaviors across domains of self-management in order to provide education and care for specific management domains for people living with epilepsy [26,42]. For people living with chronic illnesses, Baylis and colleagues have recommended that health care systems and providers offer a comprehensive, stepped care menu for self-management support tailored to individual needs [43]. The self-management instrument employed in this study can facilitate periodic reassessment as needs may fluctuate over time to help people with epilepsy maintain optimal health.

Currently, few rigorously designed epilepsy self-management programs for children and adolescents and adults are found in the literature. In addition, these programs have only been tested in one study and have not been replicated for validation and generalizability [9]. The core dimensions of self-management contained in these studies have been limited; the interventions only covered treatment or medication [44-49,20], coping skills [45,46,49,20], lifestyle [45], seizure tracking [45,48], seizure management [49], social support [49], information seeking [49], and safety [48]. Overwhelmingly, these studies focused on limited self-management domains and few covered many critical domains. Future educational programs for epilepsy across age groups could expand on core elements of self-management as part of their intervention content [9]. For example, the Chronic Disease Self-Management Program (CDSMP) has been evaluated for people with diabetes, asthma and arthritis and encompasses many topics that span several important self-management domains such as medication adherence, physical activity/wellness, coping strategies, communications and decision-making [50,51].

Limitations

This study is not without limitations. The sample is mostly Caucasian, female and fairly well-educated, and the sample has been seen by their provider in the past year. The sample also targeted adults with epilepsy (18-year or older); while it includes some information about children above the age of 18, insight into self-management in youth with epilepsy—especially small children and teenagers—is limited. Because many patients were recruited through clinical sites, our sample also reported a rate of access to specialized care significantly higher than the national estimated rate [52]. Finally, our channels for online recruitment (research matching services, mailing lists or social networks for national non-profit epilepsy advocacy organizations) are more likely to attract individuals who already practice some of the epilepsy self-management behaviors. The lateral ready belong to support networks, have access to quality information, and are actively seeking information related to their epilepsy care. Therefore, these factors limit the generalizability of the findings to other populations of people with epilepsy. The self-management instrument employed in this study is currently being tested. Future studies can validate the instrument among different populations with epilepsy.

Future research is needed to expand our understanding of different dimensions of self-management. Descriptive studies could explore determinants of better self-management and subsequent health outcomes and quality of life among different age groups. Continued testing and refinement of the self-management instrument used in this study—including an adaptation of the instruments for youth with

epilepsy or for caregivers of people with epilepsy--will contribute to further understanding of self-management domains and how these skills and behaviors vary by age, race/ethnicity, gender and seizure severity. In addition, piloting it as a self-management assessment, to tailor tools and resources for people with epilepsy and their families, is warranted. Intervention research could also test the effectiveness of education and strategies to improve patient self-management based on assessment of self-management domains.

Conclusion

Self-management is critical for people with epilepsy to function on a daily basis. The present study found that there is variation in self-management behaviors among different age groups of people with epilepsy. Health care systems that treat people with epilepsy should better understand patients' self-management skills and behaviors to better tailor education and services for them. Further research can assess domains of self-management and evaluate strategies to promote self-care and empowerment for shared medical decision-making, subsequently improving daily functioning and quality of life for people with epilepsy.

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