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The association of stigma with self-management and perceptions of health care among adults with epilepsy[☆]

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Abstract

Objective. The purpose of this study was to examine the perception of stigma among adults with epilepsy including its association with epilepsy self-management and perceptions of health care.

Methods. Participants for the study were recruited from two epilepsy centers and a neurology clinic. Individuals agreeing to participate in the study were asked to complete three assessments each 3 months apart. Data were collected from 320 adult men and women with epilepsy; 314 provided responses on stigma and were included in this analysis.

Results. Participants ranged in age from 19 to 75 years (mean = 43). Fifty percent of the sample was female, and 80% was white. The mean age of seizure onset was 22 years, and 76% of participants reported having had a seizure within the past year. Analysis suggests levels of perceived stigma are similar for men and women and across ethnic and age groups. However, participants who were not married or living with a partner, were not working for pay, and had limited income reported higher levels of stigma than did married participants, those working for pay, and those in higher income brackets. Participants reporting higher levels of stigma included those who had their first seizure before the age of 50 and a seizure in the last year. Participants whose seizures interfered more with activities, who rated their seizures as under less control, and who were not legally able to drive also reported higher levels of stigma. Tests of association between stigma and health-related variables revealed that participants reporting higher levels of perceived stigma also reported lower levels of self-efficacy to manage epilepsy; more negative outcome expectancies related to treatment and seizures; and lower levels of medication management, medication adherence, and patient satisfaction. However, they also reported greater management of information related to seizures. In regression analysis, income, age at first seizure, seizures during the past year, lower self-efficacy, negative outcome expectancies for seizures, and less patient satisfaction explained 54% of the variance in perceived stigma.

Conclusions. The results of the study suggest that perceived stigma is significant for people with epilepsy and is associated with factors that are known to be important in the management of epilepsy. Understanding who is at greatest risk for feeling stigmatized could lead to the development of preventive measures.

Keywords: Stigma; Epilepsy; Seizures; Self-management

1. Introduction

Stigma refers to a personal characteristic that marks someone as being different from normal and is commonly associated with illnesses and medical conditions that have visible signs or arouse feelings of dread or fear [1]. Epilepsy is a condition particularly prone to stigma

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because of the unpredictable and uncontrollable nature of seizures, which often arouse fear and concern in people who witness them. Although it is difficult to quantify the amount of stigma that people with epilepsy encounter, studies suggest that its perception is quite common. About 50% of people with epilepsy report feeling stigmatized, and about 15% report feeling highly stigmatized because of their epilepsy [2–5]. This high prevalence provides ample justification for its study. The identification of factors that contribute to stigma among people with epilepsy can yield a better understanding of the conditions that foster its development and perpetuate its existence.

The study of stigma among people with epilepsy has generated considerable interest worldwide, with many studies conducted in Europe. In early studies, investigators focused on personal characteristics such as gender, age, and employment. The results of studies suggest that although stigma appears to affect women and men equally, younger people are more likely to report these feelings than older people [6–8]. There also appears to be an association between stigma and employment. People who are not employed tend to report higher levels of stigma [3,9]. Likewise, persons who believe that their employment status is related to their epilepsy are more likely to perceive stigma [9].

The association between employment and stigma might be due in part to the nature of seizures as people with frequent seizures are less likely to be employed [9] and are also more likely to express feelings of stigma [2,6,10]. Investigators examining the role of seizures in the perception of stigma have noted that these feelings are also greater for people who still have seizures as compared with those who are seizure-free [6]. Likewise, people with tonic–clonic seizures tend to report higher levels [5], as do people with a combination of seizure types [2]. People who are older when seizures begin are less likely to express feelings of stigma, as are more recently diagnosed individuals [6].

People who report feelings of stigma tend to report other negative feelings as well. Baker et al. [2] found that people who scored higher on a stigma scale expressed more worry and more negative feelings about life. In a second study, Baker and colleagues [10] found that those who reported a greater impact of epilepsy on their daily lives were also more likely to report stigma. Choi et al. [3] found that perceptions of stigma were associated with quality of life such that those who have higher levels of felt stigma (perceived stigma) and enacted stigma (actual stigmatizing experiences) were more likely to report a lower quality of life. Feelings of stigma have been correlated with other negative feelings as well, including anxiety, embarrassment, and low self-esteem [5,8,10].

In other studies, investigators have explored the association between stigma and health variables. In one study, people reporting stigma were more likely to report long-term health problems, injuries associated with seizures, and more side effects from medications [2]. In another study, people reporting higher levels of stigma were more likely to miss taking their antiepileptic drugs (AEDs) [11]. Higher levels of psychopathology were also associated with a greater perception of stigma among adults with epilepsy [12].

These latter studies on the association between stigma and health-related variables suggest that there might be important health-related consequences that need to be identified. The primary purpose of the present study was to examine the nature of the association between stigma and self-management of epilepsy. Specifically, we were interested in knowing if people who express higher levels of stigma display less confidence in managing their epilepsy, have more negative attitudes toward outcomes associated with their treatment and with seizures, and have more difficulty managing their medications and maintaining lifestyle requirements. We were also interested in the association between stigma and the perception of health care. A secondary purpose of the study was to determine if in our sample of persons with epilepsy, stigma varied by selected personal characteristics, such as age, gender, and ethnic background, and selected seizure-related variables.

2. Methods

2.1. Procedures

Project EASE was a 3-year research study funded by the National Institute of Nursing Research. The primary aim of the project was to study self-management practices of people living with epilepsy. The institutional review boards at the researchers' institutions approved the study protocol. Following approval, the study was conducted at two sites: one in Atlanta, Georgia, and one in Boston, Massachusetts, USA. In Atlanta, participants for the project were recruited from two clinics, one devoted exclusively to people with epilepsy and the other a general neurological clinic. In Boston, participants were recruited from an epilepsy clinic. Patients visiting the study clinics for a regularly scheduled appointment were given a brief description of the study by their clinician. Patients expressing interest were referred to a study nurse who provided more information about the study and screened for eligibility. The inclusion criteria for the study were: (1) diagnosis of epilepsy for at least 1 year; (2) in current treatment for seizures; (3) age between 18 and 75 years; (4) ability to read and understand English; (5) mentally competent as judged by a health care provider; (6) willingness to participate. Exclusion criteria were (1) presence of a rapidly progressing neurological or medical disorder; (2) history of psychiatric syndrome that could limit participation; (3) exclusively nonepileptic seizures not being treated with antiepileptic drugs (AEDs); (4) history of sensitivity to photic or pattern stimulation; (5) history of significant substance abuse within the past year; (6) participation in a study of porcine cell transplantation being conducted at one of the clinics. People with a history of sensitivity to photic or pattern stimulation on EEG were evaluated individually to determine their previous use of computers and sensitivity to computer display screens. In consultation with the attending physician, people were able to participate if they had a history of photosensitivity by EEG, but did not have a seizure associated with computer use in the past year.

Eligible patients were invited to participate in the study. Participants were asked to complete three interviews at 3-month intervals (baseline, 3 months, and 6 months). Participants received $25 for each interview, and those in Atlanta received a small stipend to cover travel and parking expenses. The interviews were conducted using computer-assisted interviewing technology.

2.2. Measures

The Parent Stigma Scale developed by Austin et al. [13] was modified with permission for use in the present study to measure stigma in adults. The 5-item scale had been expanded to 10 items that together assess the degree to which a person believes that epilepsy is perceived as negative and interferes with relationships with others. Each item is rated on a 7-point scale from 1 = strongly disagree to 7 = strongly agree. Austin et al. originally developed the scale for use with parents of children who have epilepsy. We modified the wording of items slightly so that the items related to adults with epilepsy themselves. Austin et al. assessed the scale for content validity and internal consistency reliability ($\alpha = 0.78$). As evidence for validity, the scale correlates in the predicted direction with parent need for information, information needs, concerns, and mood (J. Austin, personal communication, June 1998). The α coefficient for the responses of the participants in the current study was 0.91.

Self-efficacy was measured using the Epilepsy Self-Efficacy Scale [14]. The scale consists of 33 items assessing different aspects of efficacy (or confidence) in the self-management of epilepsy. Each item is rated on an 11-point rating scale, ranging from 0 = I cannot do at all to 10 = sure I can do. Higher scores correspond to higher levels of confidence in ability to manage epilepsy. Content and construct validity had been assessed with an earlier 25-item instrument [14]. In three separate studies, self-efficacy correlated in the predicted direction with self-management, thus providing evidence of construct validity [15–17]. Cronbach's α for samples from these studies ranged from 0.93 to 0.94, and test–retest reliability was 0.81 [14]. The α coefficient for the current group of participants with the expanded 33-item scale was 0.90.

Outcome expectancy is defined as a judgment of the likely consequences of practicing self-management strategies and is operationally defined by three scales assessing outcomes expected if one follows one's treatment including taking medications, has a seizure, or manages one's epilepsy well. Each item is measured on a 5-point scale from 1 = strongly disagree, to 5 = strongly agree. Outcome expectancy related to treatment consists of 12 items with higher scores averaged over the 12 items corresponding to more positive outcome expectancies about treatment. Outcome expectancy for having a seizure is a 17-item scale with higher scores averaged over the 17 items corresponding to more negative outcomes related to seizures. Outcome expectancy related to epilepsy management is an 8-item scale with higher scores averaged over the 8 items associated with more positive outcomes related to epilepsy management. In a previous study, the treatment and seizure outcome expectancy scales were assessed for internal consistency reliability with a sample of people with epilepsy. The α coefficient for the outcomes related to seizure medications was 0.84, and that for having a seizure was 0.83 (unpublished data). The α coefficients computed for responses in the present study were 0.81 for treatment outcome expectancy, 0.84 for seizure outcome expectancy, and 0.78 for management outcome expectancy.

The Epilepsy Self-Management Scale is a 38-item scale that assesses frequency of use of epilepsy self-management practices. Each item is rated on a 5-point scale ranging from 1 = never to 5 = always. After reverse coding of negatively worded items, responses to individual items were averaged. Higher scores indicate more frequent use of self-management strategies. Content validity was assessed on the original 26-item version using the procedures described by Waltz et al. [18], yielding a content validity index (CVI) of 93%, which indicates strong agreement among the reviewers that the items measured self-management practices. Internal consistency reliability reported for a 26-item scale has ranged from 0.81 to 0.86 [15,16]. The version used for this study has an additional 12 items that address lifestyle issues and safety measures. A principal component analysis with varimax rotation was conducted to assess the structure of the scale. This analysis yielded five factors that were labeled (1) medication management, (2) information management, (3) seizure management, (4) safety management, and (5) lifestyle management. Reliabilities for the subscales ranged from 0.63 to 0.75.

Adherence was measured using the Self-Reported Medication-Taking Scale developed by Morisky et al. [19] and modified for the present study of antiepileptic drugs. The scale consists of 9 items and addresses barriers to taking medication. For 8 items, a dichotomous response category of *yes* or *no* is used. For the ninth item a Likert scale of never/rarely, once in a while, sometimes, usually, and all the time is used. Scoring is done by reverse-coding 7 of the 8 items, with *no* responses coded as 0 and *yes* responses coded as 1. The ninth item with the Likert scale is scored on a scale of 1–5. For the current analysis, the final item was coded so that the response of never/rarely equaled 0 and the other responses equaled 1. The α observed for the present sample of responses was 0.52.

Patient satisfaction was measured using the Patient Satisfaction Questionnaire—III [20]. The scale consists of 50 items that assess six aspects of satisfaction with care—interpersonal manner, communication, technical competence, time spent with doctor, financial aspects, access to care—and a summary index of general satisfaction. Each item is rated on a 5-point scale from 1 = strongly disagree to 5 = strongly agree. Internal consistency reliability coefficients obtained from the Medical Outcomes Study ranged from 0.82 for communication and interpersonal subscales to 0.89 for the financial subscale [20]. A confirmatory factor analysis was conducted to assess the internal structure of the scale. χ^2 goodness-of-fit indices indicated that the model fit the data, thus supporting a six-factor structure [20]. The α coefficients for the subscales for responses observed in the present study ranged from 0.69 to 0.94.

The Multidimensional Desire for Control scale was used to measure participants' desire for control of treatment and management decisions [21]. The scale consists of three subscales. One scale measures the desire for patient control, the second for clinician control, and the third for shared control. Each of the 17 items is rated on a 5-point disagree/agree scale, with higher scores corresponding to more desire for personal control, clinician control, and shared control. Content validity was assessed using a panel of experts who reviewed the items for congruency with the definition of control. Internal consistency reliability assessment yielded α coefficients between 0.75 and 0.86 for the three scales [21]. Construct validity revealed that correlations between the scales and relevant constructs were appreciable and in the predicted directions. Confirmatory factor analysis also confirmed the three-factor structure. The α coefficients for responses observed in the present study ranged from 0.73 to 0.84.

Information on personal characteristics such as age, gender, and marital status was collected, as was general information about epilepsy and seizures.

3. Data analysis

The first step in analysis was to perform a one-way analysis of variance to examine how stigma varied by levels of selected personal characteristics—age, gender, ethnic background, marital status, education, employment status, income—and seizure-related variables—age at first seizure, seizure occurrence, perceived severity, degree of control, activity restrictions, and driving status.

Following these analyses, we conducted tests to examine the association between stigma and the other study variables. The correlation coefficients were reviewed and those having a significant association with reported stigma were entered into a regression analysis with stigma designated as the outcome variable. Because many of the potential explanatory variables covaried, analysis of covariance (ANCOVA) models were fitted to determine the independent explanatory power of each to the variance in reported stigma. Three hierarchical models with main effects only were fitted, then a "final" model was fitted. In the first model, any personal characteristic that had a statistically significant univariate relationship with reported stigma was included. The second model included the same variables as the first, and all seizure-related variables that had a statistically significant univariate relationship with reported stigma were added. The third model included the same variables as the second, and all study variables that were statistically significantly correlated with reported stigma were added. The results of this model were evaluated, and a final model was fitted that included only those variables explaining a significant amount of variance in the third (full) model.

4. Results

4.1. Sample

A total of 314 individuals completed the stigma scale. These participants ranged in age from 19 to 75 years of age with a mean of 43.3 years (SD = 11.7) (Table 1). Slightly more than one-half of the sample (50.3%) were female; 80.3% were white, 15.9% were African-American, and 1.9% were Hispanic. Slightly more than half (51.6%) were currently married or living with a partner, and most had attended a trade school (5.3%) or college (70%). Of those who attended college, about two-thirds had obtained a college degree. Of the participants, 48.4% were employed either full- or part-time, and 27.1% did not work, attend a work program, or volunteer. About 42% of participants reported an income of $30,000 per year or less.

The average age when participants were first diagnosed with seizures was 22.3 years, and participants had had seizures for an average of 20.0 years (SD = 14.1). Most participants (76.1%) reported having had a seizure within the past year. More than one-third (41%) of participants reported some form of generalized seizure either as a primary or as a secondary type (e.g., complex partial with generalization). Almost one-sixth of the

Table 1
Personal characteristics

Variable	N	%
Mean (SD) age (years)	314	43.3 (11.7)
Gender (%)	314	
Female	158	50.3
Male	156	49.7
Race/ethnicity (%)	314	
African-American	50	15.9
Asian	1	0.3
Caucasian/white	252	80.3
Hispanic	6	1.9
Other	5	1.6
Marital status (%)	314	
Married	152	48.4
Single; never married	93	29.6
Single; living with partner	10	3.2
Separated	7	2.2
Divorced	48	15.3
Widowed	4	1.3
Education (%)	314	
Middle school	3	1.0
Special education in middle school	3	1.0
High school	62	19.7
Special education in high school	1	0.3
College, did not graduate	84	26.8
College graduate	97	30.9
Certificate, trade or technical program	17	5.3
Graduate school or higher	38	12.1
Other	9	2.9
Employment (%)	314	
Work full-time for pay	119	37.9
Work part-time for pay	33	10.5
Volunteer full-time	2	0.6
Volunteer part-time	11	3.5
Attend work program with help from others	1	0.3
Does not work	85	27.1
Other	63	20.1
Income (%)	307	
⩽$10,000	47	15.0
>$10,000–$30,000	81	25.8
>$30,000–$50,000	67	21.3
>$50,000–$70,000	49	15.6
>$70,000	63	20.1
Missing (refused)	7	2.2
Seizure type (%)	314	
Partial	122	38.9
General	129	41.1
Other	12	3.8
Unknown	51	16.2
Mean (SD) age seizures began (years)	314	22.3 (15.6)
Mean (SD) period of seizure activity (years)	314	20.0 (14.1)
Seizure in past year (%)	314	
Yes	239	76.1
No	75	23.9

sample (16.2%) were unable to classify their seizure type. On average, participants took two different medications to control their seizures. The most common medications taken were phenytoin (25.1%), lamotrigine (24.2%), and gabapentin (20.5%). Medications were taken an average of twice per day. With respect to the perception of stigma, the overall mean score for participants was 3.72 ($SD = 1.58$). The mean scores were distributed relatively uniformly between 1 and 5.5. Fewer participants scored at the higher levels of 6 and 7 (Fig. 1).

4.2. Statistical tests

The results of the comparison of mean stigma scores using analysis of variance revealed no statistically significant differences between age, gender, and ethnic background (Table 2). Participants who were never married and those who were divorced, separated, or widowed reported higher levels of stigma than participants who were married or living with a partner. Likewise, participants reporting no paid employment and incomes less than $10,000 reported higher levels of stigma than those who were employed for pay and had incomes greater than $30,000. With respect to education, participants who did not complete high school reported higher levels of stigma, and those who completed some postgraduate work reported lower levels of stigma. Mean stigma scores were also significantly higher for participants who reported not being able to legally drive, having their first seizure before the age of 50, having seizures for a greater number of years, having a seizure within the past year, having less control versus very good control of seizures, having greater seizure interference with activities, and having greater perceived severity of seizures.

Tests of association between stigma and study variables revealed that participants who reported higher levels of perceived stigma also reported lower levels of self-efficacy to manage epilepsy ($r = -0.431$); more negative outcome expectancies related to treatment ($r = -0.213$) and seizures ($r = 0.652$); and lower levels of medication management ($r = -0.200$), medication adherence ($r = 0.202$), and patient satisfaction ($r = -0.190$ to -0.350). However, they reported more positive outcome expectancies related to information management ($r = 0.159$). Perception of stigma was not related to desire for control.

In the first ANCOVA model, 11% of the variance in reported stigma scores was explained by personal characteristics. Of these, only income was statistically significant ($p = 0.04$); marital status approached statistical significance ($p = 0.06$). In the second model, which explained 16% of the variance in stigma, the seizure-related variables of age at first seizure and seizure in the past year were statistically significant. The third model, which included the study variables, accounted for 54%

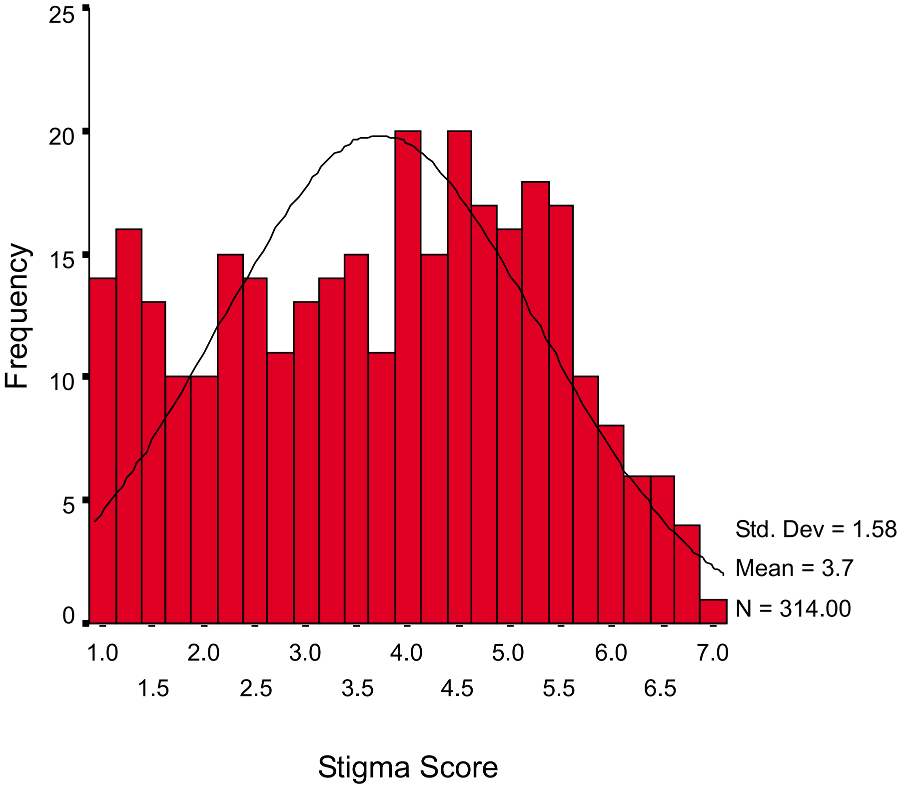

Fig. 1. Distribution of stigma scores.

of variance in stigma scores. Results from fitting this full model are summarized in Table 3, and include the estimated proportion of variance accounted for by each variable (shown in the last column). Statistically significant relationships between stigma and the study variables included more stigma with: less self-efficacy, more negative outcome expectancies for seizures, and less patient satisfaction. The final model included only the variables that were statistically significant in the full model—income, age of first seizure, seizure last year, self-efficacy, outcome expectancies for seizures, and patient satisfaction. Together these variables accounted for 52% of the total variance in stigma scores. It should be noted that outcome expectancies for seizures explained 29% of the variance in the full model and 30% in the final model.

5. Discussion

The purpose of this study was to explore the relationship between stigma and epilepsy self-management. Previous work addressing stigma and epilepsy suggested that feelings of stigma might be associated with poor health management [2,10,12]. The results of this study suggest that stigma does indeed have an influence on health-related functioning and that this association is mostly negative.

With respect to personal characteristics and their association with stigma, our findings are similar to those of other researchers. We found that stigma associated with having epilepsy is similar for men and women and across ethnic/racial groups. We did not find, as other researchers have, that younger people tend to express more of these feelings than older people [6–8]. A possible reason for the difference in findings is that only 14% of our participants were under the age of 30, thus limiting our ability to adequately assess this association. However, we did find that those whose first seizure was before their 50th birthday expressed higher levels of stigma as compared with those whose first seizure occurred after their 50th birthday. This latter finding suggests that people whose first seizure occurs early in life might hold different views about the meaning of epilepsy for themselves. Seizures are potentially more disruptive for younger individuals who must contend with a variety of social and professional issues that might no longer be as salient for older individuals.

We found that participants who were employed noted lower levels of stigma than those who were not gainfully employed, and these findings are similar to those reported by Chaplin et al. [9] and Choi et al. [3]. We also found that stigma levels were higher among participants with incomes under $10,000 per year compared with those with incomes of $20,000 or more per year and among single participants compared with married participants.

Table 2
Comparison of mean stigma scores by selected demographic and seizure-related variables ($N = 314$)

Variable	N	Mean	SD	F statistic	P value
Age group				2.0	0.091
20s	43	3.75	1.67		
30s	82	3.67	1.61		
40s	89	3.86	1.39		
50s	74	3.86	1.65		
60+	26	2.92	1.57		
Race				0.3	0.559
Caucasian	252	3.69	1.57		
Non-Caucasian	62	3.82	1.63		
Gender				1.3	0.250
Female	158	3.82	1.55		
Male	156	3.61	1.60		
Marital status				7.6	0.001
Married/partner	162	3.40	1.52		
Never married	93	3.95	1.59		
Sep/Div/widowed	59	4.22	1.54		
Income				5.9	<0.001
⩽$10,000	47	4.44	1.47		
>$10,000–$30,000	81	4.05	1.51		
>$30,000–$50,000	74	3.28	1.48		
>$50,000–$70,000	49	3.52	1.57		
>$70,000	63	3.41	1.61		
Seizure in past year				14.1	<0.001
Yes	239	3.90	1.55		
No	75	3.13	1.52		
Age at first seizure				14.2	<0.001
<50	291	3.81	1.56		
⩾50	23	2.55	1.34		

Table 3
Results of fitting the full ANCOVA model

	F	df	P value	Partial eta squared
Personal				
Marital status	1.198	2	0.303	0.008
Education	0.885	4	0.473	0.012
Work status	0.749	1	0.388	0.003
Income	2.663	4	0.033	0.036
Seizure related				
Age at first seizure	5.242	1	0.023	0.018
Seizure in past year	4.308	1	0.039	0.015
Study variables				
Self-efficacy	4.967	1	0.027	0.017
Outcome expectancy treatment	1.692	1	0.194	0.006
Outcome expectancy seizures	115.103	1	0.000	0.286
Outcome expectancy management	2.904	1	0.089	0.010
Adherence	0.017	1	0.898	0.000
Patient satisfaction	4.304	1	0.039	0.015
Medication self-management	0.003	1	0.956	0.000
Information self-management	3.538	1	0.061	0.012

As other researchers have noted, feelings of stigma tend to correspond with seizure events and experiences. In the present study, we found that participants reporting higher levels were those who had had a seizure in the last year, whose seizures interfered more with activities, who rated their seizures as more severe and in less control, and who were not legally able to drive. These findings suggest that people who must be constantly attentive to their seizure condition might be also more likely to internalize stigma and hold more negative beliefs about their treatment by others. Their constant need to maintain awareness might not give them the freedom to distance themselves from their condition; thus, epilepsy becomes a major influence in everyday life. Alternatively, it is well known that people with more difficult-to-control seizures experience greater problems with unemployment, socialization, and dependency, all factors that may affect the perception of stigma. The complex interplay of seizure severity, psychosocial consequences, and perceived stigma warrants further study to identify causal relationships and areas for study.

The tests of association demonstrate that feelings of stigma are associated with a number of health management variables. Participants who expressed feelings of stigma reported less confidence in managing their epilepsy, less positive outcomes associated with taking their medications, more negative outcomes associated with seizure events, less adherence to taking medications, and more difficulty with managing their medications. With respect to health care, participants with higher levels of stigma reported lower levels of satisfaction with health care in all areas assessed: interpersonal, communication, technical competence, time spent with doctor, financial aspects, access to care, and a summary index of general satisfaction. Our findings extend those of other investigators who have found that stigma is associated with long-term health problems, injuries associated with seizures, more side effects from medications, and less adherence to medication [2,11].

In regression analysis, the results showed that the factors most closely associated with stigma were: lower levels of self-efficacy to manage epilepsy, negative outcome expectancies related to seizures, and lower levels of patient satisfaction. Thus, as expected, participants expressing higher levels of stigma also expressed less confidence in their ability to manage their epilepsy. With respect to their relationship with health care professionals, people expressing greater feelings of stigma also noted less satisfaction with their relationship with doctors and other health care providers. They also seemed to be rather pessimistic about their seizures, believing that having seizures interferes with their lives and leads to negative outcomes such as injury, job loss, and negative reactions by others. Because perceptions of seizures explained a large proportion of variance in stigma, it is important to examine the association between these variables more closely in future research.

5.1. Implications for care

In 1997, the Centers for Disease Control and Prevention, in conjunction with the Epilepsy Foundation, the American Epilepsy Society, and the National Association of Epilepsy Centers, held a multidisciplinary conference to examine priority issues for epilepsy as a public health problem [22]. Stigma was identified as a major barrier to effective self-management for people with epilepsy. Discussion and research into the causes, consequences, and interventions to combat stigma are progressing. The results of this study reinforce the complexity of and interrelationships of stigma and self-management that are affected by and can influence both physiological and psychological aspects of epilepsy. For example, patients are asked to manage a very complex disorder with many potential consequences on their daily life. Yet they do not feel confident in their own abilities to do so, nor are they satisfied with the medical care they receive. Effective models of care, including self-management health education programs, must consider the range of interventions that are necessary to address perceived stigma and its consequences.

5.2. Limitations

This study examined perceptions of stigma and self-management practices from 314 adults with epilepsy at two locations. While both sites are tertiary care centers for epilepsy, the Atlanta site also sampled patients from a general neurology clinic. Both sites cared for people with epilepsy of varying severity. Analyses of socioeconomic status showed that the rate of unemployment was similar (27%) to the prevalence of unemployment (25%) found in the Epilepsy Foundation Cost of Epilepsy Study but the severity of seizures was greater [23]. In the current study, 76% of patients had experienced a seizure in the past year, and most had had seizures for an average of 21 years. Thus, while little can be said about perceptions of stigma in patients with new-onset or well-controlled seizures, this analysis does extend our understanding of stigma and self-management in people who continue to have seizures and who struggle to find ways to manage and cope with their epilepsy. Finally, the study employed a cross-sectional design and, thus, casual relationships cannot be inferred from the results.

6. Conclusions

Perceived stigma coexists with negative beliefs about management of epilepsy, especially the confidence to manage epilepsy, the outcomes associated with seizures, and the relationship with physicians, nurses, and other health care professionals. People with epilepsy who feel stigmatized also experience more problems with seizure control and severity. Interventions to identify patients with high levels of perceived stigma more readily are needed to tailor health education and counseling efforts appropriately. Additionally, combating stigma may require both medical and psychosocial interventions necessary to change the multifactorial causes and consequences of stigma.

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