



## Fostering epilepsy self management: The perspectives of professionals

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### ARTICLE INFO

#### Article history:

Received 2 July 2010

Revised 27 August 2010

Accepted 28 August 2010

#### Keywords:

Epilepsy

Disease management

Self management

Psychosocial

Partnerships

Interventions

Clinical care

Professional perspectives

Key informant

Qualitative research

### ABSTRACT

Epilepsy clinical, academic, and human service professionals (N=101) were surveyed regarding the challenges people with epilepsy face managing their condition. 30% of the respondents had personal experience with epilepsy. Interviews were transcribed and coded into themes. Response differences by profession and personal experience were examined using chi-squared tests. The two greatest challenges reported most frequently for people with epilepsy were finding high quality health care and managing psychological and emotional effects. The two most important epilepsy outcomes were seizure control and quality of life. The two greatest challenges facing clinicians were too little time with patients and limited clinical focus. The two main weaknesses in the field were insufficient research and narrow approaches to addressing epilepsy. Significant differences in responses across professions were evident as were differences according to personal experience with epilepsy. Few clinicians cited quality of care as a major challenge ( $p < 0.0001$ ) compared to other professions. Few respondents with personal experience with epilepsy cited stigma as a challenge ( $p = 0.006$ ).

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### 1. Introduction

The importance of enabling self management among people with epilepsy has received increasing attention in the recent past [1–3]. Self management has been defined as both the process of managing epilepsy and the steps or behaviors necessary for people to control seizures and manage the effects of having a seizure disorder [3]. Models for self management interventions have been proposed [4–14], and some of these have been evaluated in randomized and controlled studies [7–14]. Most conceptions of self management of chronic disease have evolved to envision a partnership between the person and the clinical care provider [15]. This formulation of self management recognizes a) that chronic conditions require medical services and assistance from a clinician and b) that the experts in the day-to-day challenges of management are the patients [16]. Effective management requires full and equal participation on each side of the partnership. Epilepsy management can also be facilitated by community-based social service professionals, whose role in this process is often overlooked.

Therefore, to fully understand ways to help individuals learn how to be effective self managers, two aspects must be considered. First are the management challenges as experienced by patients [17–20]. Second are the perspectives of health and human service professionals who work to foster self management in the people they serve. These perspectives will shape provider treatment, advice, and counseling and will influence the partnerships they create with their patients and clients. This study set out to determine how nationally recognized professionals working in epilepsy view challenges facing patients and how they think patients can best be assisted to be self managing.

### 2. Methods

All study procedures were approved by the University of Michigan Institutional Review Board and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki; all respondents provided informed consent prior to inclusion in the study. The development and conduct of the research were guided by an expert panel of people with epilepsy, clinicians and other health professionals working with the condition. This advisory panel of eight members was initially established through the University of Michigan's participation in the U.S. Centers for Disease Control's Prevention Research Centers Managing Epilepsy Well Network. Advisors contributed to the identification of individuals to recruit into the research, development of topical areas to

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receive emphasis in the study survey, and selection of queries to include in interviews.

### 2.1. Recruitment

An initial list of 110 names was provided by the study advisors. To participate in the study, an individual needed to meet the following criteria: represent a profession working closely with people with epilepsy (e.g. medicine, nursing, social work, academic research, and health education); be currently employed in a position involving services or studies related to epilepsy patients or clients; be recognized as making contributions to the understanding of epilepsy in his or her organization or community; and be more broadly considered a national or international thought leader. Participants also had to be willing to participate in an hour long telephone interview.

Subsequent to the development of the initial list, a snowball sampling approach was utilized. Each epilepsy professional was asked at the end of his/her interview to suggest up to three names of other individuals meeting the study criteria. New names were sought until names already on our list emerged, that is, until no new names were provided beyond those in hand. This approach yielded a potential study population of 186 unique names of national and international leaders who could serve as key informants for the research.

Potential informants were initially contacted by research staff in an email message describing the project. If email addresses were not available, telephone contact was made. If initial contact yielded no response, two further messages and a final phone call were employed. For willing participants, a convenient interview time was scheduled, and an informed consent form was mailed. The final study population consisted of 101 epilepsy professionals who could be reached, agreed to participate, and were interviewed.

### 2.2. Data collection

Two trained interviewers conducted the telephone survey. Prior to the start of the interview, the interviewer read verbatim the informed consent document, and the interviewee was asked to verbally affirm his or her consent to participate and to be audio recorded. The consent process and the interview data were recorded digitally and stored as a file on a secure University computer network.

Interviews lasted 40 min on average. In a few cases, due to time constraints, questions were posed in two separate sessions. Interviews were transcribed verbatim.

### 2.3. Questionnaire items

Survey queries were a combination of closed- and open-ended questions. In addition to demographic information about the respondent, the items were clustered into 7 areas identified as important by the advisory panel members. These comprised the following: challenges to self management; the primary management action of a person with the condition; the greatest difficulty clinicians face in providing service; the most important outcomes of epilepsy interventions; barriers to participation in interventions by people with epilepsy; deficiencies in current interventions; and other suggestions for fostering self management.

### 2.4. Data analysis

Frequencies on all closed-ended items were computed. For open-ended responses, transcripts were imported in NVivo 8, a qualitative data coding and analysis software package by QSR. All responses were coded into thematic groups using an iterative process which allowed for multiple codes for a single phrase that represented multiple ideas. After coding, summaries that described the responses in the most common thematic groupings were written for each interview item.

Direct quotations from respondents were then selected to illustrate various themes of professional perspectives.

For seven selected survey items, the most mentioned responses were examined to see if percentages of respondents citing themes varied significantly among the major respondent professions (clinicians, social service providers, and academicians) and by whether or not the respondent had personal experience with epilepsy. "Personal experience" was defined as either having epilepsy or being the close relative of a person with epilepsy. A chi-squared test of homogeneity compared these groups to see if the proportion of respondents in each differed. Difference at the  $p < 0.05$  level was considered significant.

## 3. Results

### 3.1. Respondents

Participating individuals were experienced professionals in epilepsy averaging 16 years of work in the field. The great majority (95%) were based in the United States and represented all regions of the country. The 101 respondents could be classified into the following categories: clinicians (41%), social service providers (41%), academic researchers (16%), and other (3%). Of these individuals, 14% worked in the field of mental health. Approximately one third of the clinicians were neurologists, one third nurses, and one third psychologists, neuropsychiatrists, social workers and clinical coordinators.

The 41 social service professionals worked in national and international voluntary organizations, the vast majority of which focus exclusively on epilepsy. The 16 academic researchers were primarily professors in behavioral sciences, public health, and clinical specialties.

The majority of the respondents (71%) were female and Caucasian/white (96%). Thirty percent of the respondents had personal experience with epilepsy.

### 3.2. Themes regarding enhancing self management

Table 1 presents the self management behaviors that the key informants think people with epilepsy need to do in order to best manage their condition. The first two, compliance with the medical regimen and learning about the disorder, were each considered the most important behaviors by about a third of the respondents.

Table 2 illustrates the respondents' thematic views of the most significant challenges that people with epilepsy face in managing their disease.

Quality and availability of care predominated as concerns among respondents. Statements reflected both the need for enhanced application of clinical information and the dilemma of an inadequate health care delivery system. For example:

"...there are so many without adequate health care that are simply continuing to bounce from emergency room to the street, or are being treated by physicians who are not specialized in epilepsy, that getting seizure control can be very difficult." "...I

**Table 1**  
The primary management action of a person with epilepsy (N = 101).

Percent of respondents	Theme
32	Comply with or adhere to the medical regimen
31	Understand/learn about the disorder
14	Accept the disorder
13	Have a good relationship/communicate well with physician
13	Have access to medication or other treatment
13	Understand and avoid personal triggers
9	Be a self advocate
9	Participate in the treatment process
7	Have social support

**Table 2**  
Most significant challenges in self management of epilepsy (N = 100).

Percent of respondents	Theme
45	Finding effective, accessible clinical care
26	Psychological and emotional effects of epilepsy
20	Stigma and lack of public understanding
15	Affording medications
15	Employment issues
14	Adherence to medical regimen
13	Cognitive difficulties
13	Understanding the disorder
12	The unpredictability of seizures
12	Gaining seizure control

talk to patients who say [the doctor] used this big word to describe [their condition] and they don't know what the words [mean]. They say "I have partial complex seizures" but they don't know what that means...It is confusing to listen to a doctor [when treatment and] medicine isn't explained."

Over one quarter of the respondents found psychological effects to be the biggest challenge for people with epilepsy. These most often included denial, fear, hopelessness, and depression. For example:

"Newly diagnosed patients [often] were unconscious when these things happened to them. It's all hearsay to them and so there is some resistance at first to accepting their diagnosis." "Depression and a cycle of hopelessness, and not being able to see entirely a reason [for the condition leads to] kind of giving up because [nothing] seems to matter. Their quality of life doesn't seem to improve..."

Stigma and lack of public understanding were top concerns for about one fifth of the respondents, representing significant challenges to effective management. For example:

"The kids are treated differently by their peers, differently by community at large and by doing that they have a lack of self esteem. If you don't have any self esteem then you're not going to be able to do any self management." "People in general, the public that I meet, have an idea that epilepsy means grand mal seizure. You fall down. You have convulsions...but that's not the most common form. [Some who have seizures] appear to be mentally ill, intoxicated when actually they are having seizures."

Being able to afford medications was considered the most pressing patient challenge for 15% of these professionals. Necessary medications are often expensive for those without adequate insurance. Financial issues are further complicated by the fact that people with epilepsy often experience difficulty in maintaining employment. For example:

"In this economic climate...there's the very real idea of, 'if I have a seizure at work, am I going to lose my job, and if I do, how am I going to pay for my medication?'" "...with the cost of epilepsy medications, I think there are a lot of people with epilepsy who are skipping drugs, or are breaking pills [or] are not taking it at all. They are having seizures, living with seizures, not telling doctors that they are having seizures...This impacts their work and everything else...because they don't have good insurance..."

Employment in general was viewed as the most important challenge by another 15% of respondents. The combination of seizures, cognitive difficulties, inability to drive, and other comorbidities can reduce or limit employment options for people with epilepsy. For example:

"I've worked with a number of people [who have had] seizures at work and in spite of all the ADA stuff...employers often find a way

around that, those restrictions. The person finds themselves out of a job. Repeatedly."

Medication adherence was the top patient problem for about another 15% of health professionals. Many things can reduce patient motivation to follow a prescribed regimen. Uncomfortable side effects can reduce willingness to stay on schedule. Even feeling healthy as a result of prolonged adherence may lead to skipping medication because of a confidence that the epilepsy is safely managed or well enough to skip dosages. Cognitive difficulties stemming from both the condition and the medicines themselves can affect adherence. For example:

"...particularly people who have chronic epilepsy...have cognitive deficits [that] makes it very difficult for them to understand directions and follow directions... remembering what to do and when to do it, even for those with the best intentions, can be very difficult."

Another subset (13%) reported that cognitive difficulties are the most problematic aspects of managing epilepsy. In addition to interfering with adherence to the medical regimen, these can affect relationships, education, and employment. For example:

"People [who] have epilepsy often have specific cognitive problems related to the same damage in the brain that's causing the epilepsy. [This] makes it very difficult to be fully oriented all the time and have normal...memory. I would say that cognitive [difficulties] is a huge factor."

The unpredictability of seizures was seen by another sizeable subgroup as the most compelling challenge. This unpredictability may be a source of fear and stress. It can limit a person's ability to plan for the future both short and long term. For example:

"Some people, they believe that they have no control because they have epilepsy...If you don't feel like you're in control of your life, you're going to have issues. And when you're not in control of your body, that really magnifies [everything]...There's nothing I can do. I can't work. I can't ride the bus. I shouldn't cook." "Even for myself, being controlled for so many years, it's always still in the back of my mind. It could happen, and how is that going to change my life? What is going to be different?"

Table 3 provides the themes across the statements of the respondents that depict their perspectives on the greatest difficulty that clinicians face in caring for their patients with epilepsy. Perhaps not surprisingly, time limitations were seen by over a third of the respondents as the greatest difficulty clinicians face. They opined that, especially in today's health care environment, consultation time is limited, clinicians feel overworked, and there is great pressure to move patients quickly through the clinic or office. Clinicians are thought to lack time to educate their patients and teach management skills, nor do they have time to locate and provide other resources that might help people with epilepsy. For example:

"So much time is taken up with assessment of how the patient is doing, getting patient histories...doing the labs and then changes

**Table 3**  
Greatest difficulty faced by clinicians (N = 99).

Percent of respondents	Theme
37	Time limitations
25	Limited focus of clinicians
11	Finding the best course of treatment
11	Lack of supportive services
11	Patient does not follow care plan
10	Inaccurate reporting from patients
10	Access to medications

needed in treatment...they [clinicians] don't really get into a lot of [self] management." "...one of the greatest difficulties right now is being able to develop a relationship with people, where you can get into things a little bit more."

About a quarter of the respondents identified the greatest challenge for clinicians as their limited focus. By this they mean that, essentially, physicians are trained to diagnose and treat disease. This narrow view does not account for more holistic issues such as quality of life and the psychosocial aspects of living with a chronic condition. For example:

"[Physicians] need to be able to think a little more globally, not focus just on the seizures but beyond what is going on in the [patient's] brain. [They need to think about] the rest of the person...co-morbid conditions, social effects...They really need to be able to communicate and ask...what their needs are beyond... seizure control."

About 10% of the respondents reported that the greatest difficulty for clinicians was finding the best course of treatment for the patient. It can be a slow and frustrating process to search among the number of medications and other treatment options for the one that is most effective for an individual. Clinicians face even greater challenges with patients with drug-resistant seizures when no treatment is effective. Respondents discussed emotional challenges faced by clinicians, frustration, and a sense of helplessness when no improvements result or when there are setbacks such as intolerable medication side effects. For example:

"There is really no panacea for epilepsy. There is no one thing that cures it all. I think that [this] can be really difficult because the patient comes in and expects the physician to know everything—to say here is your magic pill. It doesn't work like that."

A number of these key informants (about 10% for each theme) indicated that priority challenges for clinicians were lack of supportive services, patients' failure to independently follow the care plan, and inaccurate patient reports. For example, the lack of supportive and complementary services within and outside the clinical setting was discussed:

"Most clinicians don't have the benefit of working in a multi-disciplinary team [whose members] are experts in epilepsy. A particular gap is psychiatric resources. [Epilepsy] is a multi-disciplinary disease. It needs to be approached from an inter-disciplinary angle."

Patients who appear not to be taking charge of their lives and their illness and who do not seem to be accountable for managing it were described:

"...there seems to be a lack of interest on the part of some patients [in managing the condition], a sort of deference to the family member or a significant other as the person that needs to manage for them rather than the patient wanting to take responsibility."

Inaccurate reports from patients that interfere with drawing an accurate picture of the condition and developing appropriate treatment steps were described as a challenge for clinicians. Many reasons for inaccuracy were cited: patients may fear losing their driver's license, not report non-medical issues, not understand the disorder well enough to recognize relevant information, forget how many seizures they had or simply not realize that they have had a seizure. For example:

"We don't have a marker that is independent of the person telling us they had seizures or how many seizures they had. I think this is

a huge limitation for clinicians. We don't have a CAT scan. We don't have a hemoglobin A1C. If we had some way of measuring seizures, an objective measure of seizures, that would be an amazing [break through]."

Table 4 presents the respondents' views of the most important outcomes a successful epilepsy intervention can achieve.

For over a third of these professionals seizure control is the marker of success. For example:

"Of course our major goal is to have people seizure free. Well, we can't always get that but we can improve seizures many times." "More and more research has shown how persistent seizures are associated with many more problems. [They are] associated with higher rates of unemployment, higher rates of mood disorders, greater risk of SUDEP [Sudden Unexplained Death in Epilepsy]...The risks associated with poorly controlled seizures are so high, I want to ...be able to impact seizure control."

Almost a quarter of the key informants said quality of life is the most important outcome for interventions. These respondents described that although absolute seizure freedom is not always feasible, coping with seizures and mitigating other stress factors can significantly improve the quality of life for people with epilepsy. For example:

"Improved quality of life, that's what it is all about. People want to be happier and even though you may not be able to reduce seizure frequency, if you can help people cope with [the effect of seizures] ...so they do their best despite having seizures, and they are able to manage the other things that impact their quality of life, that would be key."

About another fifth of the respondents reported that helping people to develop confidence and a sense of control was the most important outcome of an intervention. For example:

"An epilepsy self management program has to improve a person's confidence in their ability to [do what is needed to control the condition and its effects]. If they don't believe that they can impact their seizures or believe that they can impact their goals, then none of those will be achieved. Self efficacy is...a mediator but also an outcome."

Smaller numbers (about 10% for each theme) thought independence and improved self management skills would be the most compelling outcomes of an intervention. For example:

"I am not sure it is completely realistic, but some portion of your patients would [become] independent because of being seizure free. ...An increased number [could] be employed...drive...The independence factor is really big in this population of people." "...the clients that I deal with that are really good self managers, they're empowered to know their own body in terms of 'I understand what is happening to me, even if I don't remember the event'...Understanding how lifestyle impacts seizures...why

**Table 4**  
Most important outcomes of epilepsy interventions (N = 98).

Percent of respondents	Theme
38	Seizure control
23	Quality of life
20	Confidence and a sense of control
10	Independence
10	Improved self management skills

**Table 5**  
Key behavioral objectives for an epilepsy management intervention (N = 99).

Percent of respondents	Theme
60	Compliance/adherence with medications
31	Healthy lifestyle and trigger reduction
24	Acceptance, attitude and psychological coping
17	Understanding epilepsy
14	Recognition of own triggers
14	Advocacy for oneself
12	Communication with health care provider
12	Accurate recording of seizures
11	Awareness of and use of resources

medications work and how they work, and understanding how timing is important...”

Table 5 provides the behavioral objectives that for key informants would comprise the top three aims of an intervention program for people with epilepsy. Over a half found that skills related to compliance with medicine were the most important behavioral objective. Almost one third reported that aspects of healthy life style and reduction of seizure triggers were the priority management behaviors. Another quarter stated that acceptance of the condition, positive attitudes toward it, and psychological coping were the concepts and behavioral skills most important to include in an intervention.

Table 6 illustrates the professionals' views of barriers for people that lead them not to participate in interventions designed to help them manage their condition more effectively.

For more than half of these key informants, transportation is the top reason that involvement in epilepsy interventions is low. Several ways to address the transportation problem were offered, including the following approaches: using telemedicine, phone, and the internet; locating programs on public transportation lines or in clinical settings where people already have worked out their transportation needs; and partnering with transportation assistance providers.

For one third of the respondents, psychological barriers were voiced as the greatest threats to participation. Denial, mood disorder, fatalistic outlook, and low self esteem were cited as part of this problem. Suggestions to minimize these obstacles included: public awareness and education campaigns; referrals to affordable counseling; networking with successful peers; one on one education in the clinical setting; encouraging physical activity as a way to elevate mood; employing a health care team; and finding ways to assess readiness for self management.

When asked about weaknesses and challenges in the field of epilepsy self management, the respondents reported those items listed in Table 7.

About a quarter of the key informants reported that more research is needed and particular areas for study were cited including: epidemiological research concerning differences among races and

**Table 6**  
Barriers to participation in interventions by people with epilepsy (N = 98).

Percent of respondents	Theme
54	Transportation
36	Psychological barriers
23	Financial barriers
21	Stigma
16	Self management not valued or understood
16	Time conflicts
15	Lack of awareness that program or help exists
13	Lack of access to health care
11	Program not available
11	Cognitive issues

**Table 7**  
Weaknesses and challenges in the field of epilepsy self management (N = 93).

Percent of respondents	Theme
24	Insufficient research
20	Narrow approach to addressing epilepsy
15	Lack of awareness and stigma
14	Programs not accessible
11	Lack of funding
11	Health care system and insurance
8	Need to individualize interventions

ethnicities; epilepsy in women of childbearing age; practical and social problems confronting people with epilepsy; predicting and preventing seizures; determinants of self management behavior; impact of seizures on stress and sleep; and how people with epilepsy access and manage information. Another fifth reported that a serious weakness in the field is the narrow approach to addressing epilepsy and its complications. Examples include limited use of multidisciplinary teams and insufficient consideration of broader social, psychological and economic influences. Additional deficiencies were echoed in the responses that describe the challenges that people with epilepsy face in managing their condition.

3.3. Differences in perspective by profession and experience living with epilepsy

Table 8 presents the top five response themes to the question what is the greatest challenge a person with epilepsy faces? Only two items varied significantly by respondent profession type: clinical care ( $p < 0.0001$ ) and affording medications ( $p < 0.018$ ). Most researchers (88%) cited clinical care (accessibility and quality) issues as a challenge compared to 56% of social service providers and only 22% of clinicians. Among clinicians, cognitive difficulties (20%) and compliance (20%) replaced employment and affording medications in the group's top five responses; these themes do not appear in Table 8 because only the top five themes among all respondents are reported in this table and those that follow. Affording medications was cited by 27% of social service providers, 10% of clinicians, and no researchers. Among researchers, gaining seizure control (25%) replaced affording medications in the top five challenges.

Table 9 shows that for the same question, only one response theme varied significantly by whether the respondent had personal experience with epilepsy: stigma and lack of public understanding ( $p < 0.006$ ). Only 3% of those with personal experience cited stigma and lack of public understanding as the greatest challenge, whereas 27% with no personal experience did. Instead, cognitive difficulties (17%) were among the top five cited by people with personal experience. Affording medications approached statistical significance ( $p = 0.063$ ); 27% of those with personal experience cited affording

**Table 8**  
Greatest challenge to management by respondent profession type.

Theme	Clinicians (n = 41)	Social service providers (n = 41)	Researchers (n = 16)	p-value
Clinical care	22%	56%	88%	$p < 0.0001^a$
Psychological effects	32%	20%	31%	$p = 0.410$
Stigma and lack of public understanding	15%	24%	25%	$p = 0.485$
Employment	12%	15%	19%	$p = 0.814$
Affording medications	10%	27%	0%	$p = 0.018^a$

<sup>a</sup> Percentage of respondents citing theme varies significantly by profession type ( $p < 0.05$ ).

**Table 9**  
Greatest challenge by whether respondent has personal experience with epilepsy.

Theme	Personal experience (n = 30)	No personal experience (n = 71)	p-value
Clinical care	60%	43%	p = 0.131
Psychological effects	20%	27%	p = 0.460
Stigma and lack of public understanding	3%	27%	p = 0.006 <sup>a</sup>
Employment	17%	14%	p = 0.766
Affording medications	27%	10%	p = 0.063

<sup>a</sup> Percentage of respondents citing theme varies significantly by whether the respondent had personal experience with epilepsy (p < 0.05).

medication compared with only 10% of those with no personal experience.

Table 10 shows that only one item varied significantly by respondent profession when queried about the most important thing a person can do to manage epilepsy: medication compliance (p = 0.046). Medication compliance was the most frequently mentioned response from clinicians (46%), but it was mentioned by only 24% of social service providers and 19% of researchers. The most frequently mentioned response among researchers (31%) and social service providers (27%) was the need for people to understand their own condition. Though not statistically significant, only 2% of clinicians cited a good relationship and communication with a physician whereas it was cited by 17% and 19% of social service providers and researchers, respectively.

When the topic was the greatest challenge facing clinicians in helping their patients, Table 11 shows that only one item varied significantly by respondent profession type: lack of supportive services (p = 0.031). Lack of supportive services was mentioned by 20% of clinicians, 5% of social service providers and no researchers. Among researchers, keeping up-to-date medically (19%) and providing self management education (19%) were in the top five, and among social service providers, financial barriers (15%) and accurate reporting from patients (17%) were in the top five most frequently cited responses.

Table 12 illustrates that on the question regarding the greatest difficulty clinicians face, only one item varied significantly by whether the respondent had personal experience with epilepsy: finding the best course of treatment (p = 0.017). Sixteen percent of the respondents with no reported personal experience with epilepsy mentioned finding the best course of treatment, whereas none of the respondents with personal experience did. Among those with personal experience, more commonly cited themes pertained to lack of accurate reporting by the patient (19%) and trouble clinicians have keeping up-to-date medically (13%).

Table 13 shows that two items related to the most important outcome of a self management intervention varied significantly by

**Table 10**  
Most important management action by respondent profession type.

Theme	Clinicians (n = 41)	Social service providers (n = 41)	Researchers (n = 16)	p-value
Medication compliance	46%	24%	19%	p = 0.046 <sup>a</sup>
Understand their own condition	32%	27%	31%	p = 0.878
Accept the disorder	10%	20%	13%	p = 0.440
Have good relationship and communication with physician	2%	17%	19%	p = 0.064
Access to medication	17%	15%	0%	p = 0.220

<sup>a</sup> Percentage of respondents citing theme varies significantly by profession type (p < 0.05).

**Table 11**  
Greatest difficulty faced by clinicians by respondent profession type.

Theme	Clinicians (n = 41)	Social service providers (n = 41)	Researchers (n = 16)	p-value
Time limitations	37%	39%	31%	p = 0.861
Limited focus	22%	22%	38%	p = 0.417
Finding best course of treatment	7%	12%	19%	p = 0.455
Lack of supportive services	20%	5%	0%	p = 0.031 <sup>a</sup>
Patient does not follow care plan	15%	7%	13%	p = 0.568

<sup>a</sup> Percentage of respondents citing theme varies significantly by profession type (p < 0.05).

respondent profession type: quality of life (p = 0.038) and improved self management (p = 0.029). About the same percentage of clinicians and researchers mentioned quality of life (32% and 31%), but it was cited by only 10% of social service providers. No side effects replaced improved self management in the list of top five responses for social service providers (7%) and clinicians (12%). A greater percentage of researchers (25%) cited improved quality of life whereas clinicians (10%) and social service providers (2%) cited this outcome much less frequently.

No other differences by profession or experience with epilepsy were observed.

#### 4. Discussion

The 101 national and international thought leaders who provided responses in this research represented clinical, academic, and human service professions providing care to people with epilepsy. Their views draw a compelling and challenging picture of epilepsy and the potential for more effective management of the condition.

##### 4.1. People with epilepsy and their families

The professionals in this study described a number of challenges people with epilepsy encounter on a day-to-day basis. Several overarching themes emerged from the interviews, including emotional, educational, and practical challenges that often interfere with the daily functioning of people with epilepsy. Psychological and emotional effects of having epilepsy, including denial and depression, were cited as significant challenges. Fear and anxiety were central challenges associated with the unpredictable nature of the condition and the resulting view of patients that they are always waiting for or expecting the next event. Cognitive difficulties caused by the disorder or its treatment

**Table 12**  
Greatest difficulty faced by clinicians by whether respondent has personal experience with epilepsy.

Theme	Personal experience (n = 30)	No personal experience (n = 71)	p-value
Time limitations	26%	41%	p = 0.180
Limited focus	32%	20%	p = 0.210
Finding best course of treatment	0%	16%	p = 0.017 <sup>a</sup>
Lack of supportive services	3%	14%	p = 0.165
Patient does not follow care plan	13%	11%	p = 1.00

<sup>a</sup> Percentage of respondents citing theme varies significantly by whether the respondent had personal experience with epilepsy (p < 0.05).

**Table 13**  
Most important outcome by respondent profession type.

Theme	Clinicians (n = 41)	Social service providers (n = 41)	Researchers (n = 16)	p-value
Seizure control	46%	34%	25%	p = 0.270
Quality of life	32%	10%	31%	p = 0.038 <sup>a</sup>
Confidence/ control	22%	20%	19%	p = 0.948
Independence	12%	10%	6%	p = 0.795
Improved self management	10%	2%	25%	p = 0.029 <sup>a</sup>

<sup>a</sup> Percentage of respondents citing theme varies significantly by profession type (p < 0.05).

present significant challenges as well. Education and understanding of one's personal disorder also can be a daunting task. Because the condition manifests itself in a variety of ways particular to an individual, understanding the unique aspects of the disorder, the specific triggers to one's episodes, and what the individual needs to achieve seizure control can prove difficult for many patients. Among people who experience seizures, more practical problems include the legal restrictions related to driving a vehicle, which creates challenges across several aspects of day-to-day living. Because of this and other reasons, securing and keeping a job can be difficult, and many feel forced to give up the idea of employment when strategies to ameliorate the effects of the condition are unclear or do not work. Related to all of these overarching challenges are the perceived stigma and sense of social isolation experienced by many people with epilepsy.

Overall, these challenges reinforce observations made in studies of perceptions of health care professionals in epilepsy care [21,22]. For example, in a study that assessed learning needs of health care professionals, respondents frequently cited denial and managing multiple patient needs such as co-morbid conditions as barriers to optimal health care. These professionals also discussed the social stigma of epilepsy and the resulting prejudice that hinders employability [21]. Unlike studies on professional viewpoints found in the literature, our study included a substantial proportion of human service providers; arguably, their inclusion enhances study results with a more holistic perspective on the challenges faced by people with epilepsy and their families.

The majority of the respondents were clear about the primary desired outcomes of epilepsy care and education for people with epilepsy: seizure control, enhanced quality of life, higher levels of confidence, and independence. Behavioral routes to desired outcomes included compliance with the medical regimen; seizure trigger identification and reduction; acceptance of the realities posed by the condition; ameliorating cognitive problems; and forming a partnership with a clinician. The last of these was thought to entail several factors for patients including, for example, how to a) communicate with the clinician (ask questions, set benchmarks, comply with treatment recommendations, and make accurate reports about the clinical history); b) be a self advocate (be assertive about their needs and rights); c) draw on the social support system (including family, friends, and organized forms of support like the Epilepsy Foundation); and d) use available resources in the community and clinical settings, on the web, etc. However, the means for people with epilepsy and their families to adopt this more active role in epilepsy management were often perceived to be limited in availability and approach.

#### 4.2. Clinical care, its quality, and its costs

Themes reflected in the responses of study participants included the perception that for many people with epilepsy it takes

considerable time to get an accurate diagnosis, and clinical care often involves a difficult and frustrating process of trial and error. Similarly, it is difficult to find and obtain the services of epilepsy specialists, and multidisciplinary teams are rare. The cost of insurance and of medicines recommended for epilepsy control was thought by the majority of the respondents to be high and discouraging. The usual strategies employed in the clinical and home settings to try to ameliorate these problems (selecting second line drugs and skipping doses) were described as common cost-cutting practices that reduce the potential for effective epilepsy control.

Significant barriers to providing effective care included the reality that in most clinical settings, time with the patient is severely limited. The majority of physicians, whether specialists or general practitioners (the latter group being the clinicians providing the greatest amount of care to people with epilepsy), either do not see enough of these patients to fully understand holistically their treatment challenges or have insufficient training on how to provide effective care to them. As a result, selecting the best treatment plan, effectively engaging the patient in his or her own care, and linking to needed support services can fall outside their areas of expertise. These same barriers to effective epilepsy care have been identified in other studies of health care providers [21,23].

#### 4.3. Differences by profession and personal experience with epilepsy

One's profession and personal experience made a difference in how challenges for people managing epilepsy were seen. While researchers and social service professionals saw access to and quality of clinical care as the most daunting factors, clinicians reported in far fewer numbers that this was the greatest management challenge and instead cited compliance and cognitive difficulties associated with the disorder.

Being able to afford medicines needed to treat the disorder was not seen as a great challenge by the majority of clinicians or researchers, but about a quarter of social service professionals viewed affording medications as a great challenge for people with epilepsy. This relative inattention of clinicians to the financial barriers of antiepileptic drugs was noted by Hayes et al. [21]. In contrast, a recent study found that significantly more physicians than patients ranked cost as an important factor when considering factors that contribute to missing antiepileptic drug dosages [24].

Having personal experience with epilepsy (having the condition or having a close family member with it) also made a distinct difference in how challenges were seen. Virtually no person with personal experience with epilepsy saw stigma or lack of public understanding as a great challenge, yet over a quarter of the respondents without personal experience said this was one of the greatest challenges facing people with epilepsy. This finding is consistent with a study by Doughty et al. that found that only 17% of people with epilepsy perceived a high level of stigma and half do not feel stigmatized based on the Epilepsy Stigma scale [25]. While not all people with epilepsy perceive a high level of stigma, work by Dilorio et al. shows that perceived stigma among people with epilepsy coexists with decreased confidence to manage the disorder and its outcomes and negative beliefs about their relationships with health care providers [26].

Respondents with personal experience with epilepsy were instead far more likely to report cognitive difficulties and expensive medications among the greatest challenges that people with epilepsy face. Both these challenges were identified by people with epilepsy in previous studies [21,24,27].

These study findings suggest that views about the experience of managing epilepsy vary among professionals trying to ameliorate challenges for the people they serve. Very compelling views are those

of individuals who have both professional and personal experience with the condition. Ensuring these perspectives are shared and widely available to those in different professions may be a way to enhance management by both professionals and people with the condition.

#### 4.4. The field of epilepsy management

As a field of endeavor, work in epilepsy management was described as having significant areas of weakness where more research is indicated. Insufficient research is available describing the elements of management that are shared versus unique to individual patients. Convincing evaluations of interventions were thought to be lacking, an idea that is consistent with conclusions of recent review articles [25,28,29].

Study results also suggest that many clinical professionals take too narrow an approach to epilepsy care and fail to recognize the way the condition affects all aspects of day-to-day functioning of people with epilepsy and their families. As a result, treatment plans and support services can be inadequate for the range and intensity of problems that patients face.

Practical implications in the findings of this study concern research, training, and practice. A number of advances appear needed to more fully enable professionals to do their best work and people with epilepsy to manage more effectively. At a minimum, clinicians need to be aware of, and refer patients to, the available psychosocial and educational resources in the community such as the 50 Epilepsy Foundation affiliates in the United States and credible online sites [30].

Research that better explicates how more effective partnerships can be established between patients, caregivers, and the professionals aiming to assist them seems warranted. More robust training is indicated, as are supportive clinical environments that ensure multidisciplinary team approaches to care. In a study of learning needs of health care professionals in epilepsy care, members on interdisciplinary epilepsy care teams described ill-defined and conflicting ideas of team member roles, and the authors suggested that major stakeholders collaboratively develop an interdisciplinary guideline for clinical practice such as a continuum of care map to clearly differentiate roles and improve efficiency [21].

Studies of epilepsy nurse specialists in the clinical setting show promise [31–33], and in the United Kingdom, the non-profit organization Epilepsy Action actively supports epilepsy nurse specialists by providing seed money to enable epilepsy centers to appoint nurse specialists and through advocacy efforts to maintain their central role in patient care [34–36]. Also in the United Kingdom, the National Society for Epilepsy supports a network of volunteers in hospital neurology departments and other health care settings in the country who provide information and local resources to people with epilepsy and their families on non-medical matters [37]. In the southeastern United States, case management for low income people with epilepsy provided by professionals in social work from a non-profit, state supported epilepsy service has been shown to significantly reduce emergency room visits and improve seizure control and quality of life [38].

Refined models for self management interventions are needed, a pursuit of special interest to the Managing Epilepsy Well Network [39]. These programs must reflect holistically the concepts and skills people with the condition need to develop to optimize their sense of control and independence. Finally, stronger evidence is required pertaining to the effect of epilepsy interventions on desired outcomes such as fewer seizures, quality of life, and independence.

#### Acknowledgments

This article was supported by Special Interest Project funding through Cooperative Agreement Number 5U48DP000055-05 from

the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

The authors thank the National Center for Chronic Disease Prevention and Health Promotion, the Michigan Prevention Research Center, the colleagues who comprise the Managing Epilepsy Well Research Network, data analyst Margaret K. Wilkin, M.P.H., and all members of the project's advisory panel: Maureen Brendel, Frank Bublitz, Sucheta Joshi, M.D., Laurie Lachance, Ph.D., Amy Friedman Milanovich, M.P.H., and Linda Selwa, M.D.

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