



THE CENTER
FOR MANAGING
CHRONIC DISEASE

Putting People at the Center of Solutions

Contributing to Managing Epilepsy Well

Key Informants' Perspectives on Managing Epilepsy

March 2010



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Executive Summary: Key Informants' Perspectives on Managing Epilepsy

The 101 national and international thought leaders who provided responses to the CMCD-CMEW Key Informant telephone survey represented clinical, academic, and human service organizations 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.

People with Epilepsy and Their Families.

In addition to the challenge of obtaining effective clinical care described below, people with epilepsy were described by respondents as facing a number of challenges in day to day functioning. As the condition manifests itself in a variety of ways unique to an individual, understanding these unique aspects of the disorder, the specific triggers to one's episodes, and one's particular needs in maintaining control can be difficult for many patients. Fear and anxiety are central challenges associated with the unpredictable nature of the condition and the view of patients that they are simply waiting for the next event. Keeping a job is a problem for many patients, and a number give up on the idea of employment as ways to ameliorate the effects of the condition are not clear or are not working. Related to these factors are the perceived stigma and sense of social isolation experienced by many people with epilepsy especially teenagers and children.

The majority of respondents were clear about the primary desired outcomes of epilepsy care and education for the patient. They were thought to be seizure control, enhanced quality of life, higher levels of confidence and independence. Particularly mentioned were three means to measure some of these outcomes: 1) frequency of seizures; 2) the Quality of Life in Epilepsy Scale; and 3) the Dilorio Self Management Scale.

Routes to desired outcomes were seen as compliance with the medical regimen (especially in light of the side effects of several epilepsy treatments); trigger identification and reduction, acceptance of the realities posed by the condition; instituting precautions for potentially unsafe situations; ameliorating cognitive problems; and forming a partnership with a clinician. The last of these was thought to entail several factors for patients: a) communicate with the clinician (ask questions, set benchmarks, comply with treatment recommendations, make accurate reports about the clinical history); b) be a self advocate (be assertive about needs and rights); c) draw on the social support system (including family, friends, and organized forms of support like the Epilepsy Foundation); d) use available resources in the community, the clinical setting, the web etc. As noted below, however, the means for people with epilepsy and their families to learn this more energized role in epilepsy management are currently limited.

Clinical Care, Its Quality and Costs.

Respondents described that for many people with epilepsy it takes considerable time get an accurate diagnosis, and 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. Cost of insurance and of the medicines recommended for epilepsy control were uniformly thought 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, skipping doses) were described as common cost cutting practices that reduce the potential for effective epilepsy control.

Most clinicians were thought to face significant barriers to providing effective care. These included the fact that for most and in most clinical settings, time with the patient is severely limited. Further, 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 little or no prior 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 fall outside their arena of expertise.

In the delivery of clinical care and education to epilepsy patients, it was thought by most respondents that a clinical and community team approach, including patients and family members as part of the team, was most likely to provide the kind of holistic attention that people with epilepsy need. Further, certain intervention characteristics were thought to hold the greatest promise for success. In the view of respondents, services and programs should a)engage families along with the patient; b) be face to face either in groups or one on one; c)be continuous, facilitated by nurses or health educators, c)be based on practical models and disseminated widely (for example, by the Epilepsy Foundation and professional associations). It was the opinion of most that current research and evaluation efforts have been inadequate and available interventions limited as regards to evidence of their effectiveness and the means by which to individualize the program to the unique needs of patients.

Targeted training for professionals was also seen as needed. Education for groups i.e. specialists, general practice clinicians, nurses, mental health and social workers was recommended in addition to patient and family education. As well, education and training for teams of providers enabling them to integrate and coordinate their services was deemed warranted.

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. Researchers and social service professionals saw access to and

quality of clinical care as the most daunting factor. Clinicians reported in far fewer numbers that this was the greatest management challenge and instead cited psychological effects associated with the disorder.

Being able to afford medicines needed to treat the disease 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.

Having personal experience with epilepsy (having epilepsy or having a close family member with epilepsy) also made a difference in how challenges were seen. Virtually no person with personal experience with epilepsy saw stigma and lack of public understanding as a great challenge to people with the condition although over a quarter of the respondents without personal experience said this was one of the greatest challenges. Respondents with personal experience with epilepsy were also much more likely to report that affording medicines was a challenge, and for them, cognitive difficulties were consistently in the top five most frequently cited challenges that people with epilepsy face.

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 personal experience with the condition. Ensuring these perspectives are shared and widely available to those in different professions may be a way to enhance the care provided.

The Field of Epilepsy Management.

As a field of endeavor, work in epilepsy was described as challenged by several weaknesses that were thought to be characteristic. As noted, insufficient research describes the elements of management that are shared versus unique to individual patients. Convincing evaluations of interventions are lacking.

Clinical professionals take too narrow an approach to epilepsy care and fail to recognize the way the condition affects all aspects of functioning. As a result treatment plans and support services can be inadequate for the range and intensity of problems that patients face.

Too few programs in general and too few evidence based programs are available for practitioners, community agencies, and families themselves to choose from. In addition, several groups are particularly overlooked regarding epilepsy education including people with co morbid conditions and developmental disabilities; people with intractable and refractory epilepsy; low income patients; and those from diverse racial and ethnic backgrounds.

Finally, lack of funding for support programs, as well as, research and evaluation is a problem. Even more so is the fact that inadequate insurance coverage for many epilepsy patients is a deterrent to their ability to obtain needed care and services.

Methods

The study was approved for human subjects research by the University of Michigan's Health Institutional Review Board (HUM00024560).

Development of Survey Instrument

Survey questions were developed through a collaborative process between the research team and members of the project's expert advisory panel. The panel is composed of two epileptologists, the President and Education Director of the Epilepsy Foundation of Michigan, a person with epilepsy, a parent of a child with epilepsy, a dissemination expert, and an evaluation expert. Questions were revised several times and the number of questions was reduced in order to shorten average interview time after a pilot interview was conducted. The final survey instrument can be found in *Appendix A* of this report.

Recruitment

An initial list of approximately 110 key informants was developed from internet searches of national and international epilepsy organizations, literature searches of epilepsy self management research, and recommendations from members of the expert advisory panel and the Managing Epilepsy Well Research Network (www.sph.emory.edu/ManagingEpilepsyWell/). The research team solicited names of national and international thought leaders and those with thorough knowledge of epilepsy self management from clinical, social service, and academic research backgrounds in order to gather diverse perspectives.

Names were also solicited using a snowball approach, wherein respondents were asked for up to three names of individuals who they thought should also be interviewed to better understand what is needed and what would be most effective in the area of epilepsy self-management. The vast majority of respondents were very willing to recommend names and provide contact information. Most of the individuals recommended by respondents were contacted, but discretion was used in the latter half of data collection in order to achieve better balance among the numbers respondents working in clinical, social service, and research areas.

The individuals were initially contacted by the Principal Investigator or Project Manager via an e-mail message that briefly described the project and asked if they would be willing to participate in a telephone interview. In the few cases where an email address was not available, the individual was called on the telephone. Individuals were asked to recommend others if they were unable or unwilling to participate.

If initial contact yielded no response, 1-2 follow-up e-mail messages were sent, followed by a phone call. Those who expressed interest were provided with any requested additional

information, and an interview time convenient to the respondent was scheduled. Respondents were sent a copy of the informed consent and a list of the interview questions prior to the interview with a message indicating that although it is not necessary to review the questions before the interview, the questions are available for those who are able and wish to do so.

A total of 224 potential respondents were contacted throughout the project, and the response rate was 45%. Respondents recommended 217 potential respondents, and 186 of those were unique names. Seven individuals were recommended by more than one respondent, and five of the seven were interviewed.

Data collection

All interviews were conducted by the Project Manager or the study's graduate student research assistant. Prior to the start of the interview, the interviewer read, verbatim, the informed consent document that was sent to the respondent prior to the interview. The respondent was asked to verbally affirm their consent to participate and to indicate if they agreed to being audio recorded during the interview. The consent process was audio recorded digitally and stored as an audio file on a university computer hard drive.

Interviews lasted approximately 40 minutes on average. In a few cases, due to time constraints, interviews were broken into two sessions. Only one person was interviewed at a time in all but one case, where two respondents participated in a single interview. The interviews were audio recorded to digital files; the interviewer also took brief notes in the case of technical difficulties, or more detailed notes if the interview was not being recorded. Four of the 101 interviews were not recorded either due to technical problems or at the request of the respondent; one respondent opted to submit written answers in lieu of a telephone interview.

Interviews were transcribed verbatim.

Analysis and Presentation

Transcripts were imported in NVivo 8, a qualitative data coding and analysis software package by QSR, and all responses were coded into thematic groups using an iterative process that allowed for multiple codes for a single phrase that represented multiple ideas. After coding was complete, summaries that described the responses in the most common thematic groupings were written for each interview question, and direct quotations from respondents were added to illustrate various individual perspectives. After the summary paragraphs for each question, a bulleted list of the less common responses is included.

For seven survey questions, the top five most prevalent responses mentioned were examined to see if the percentage of respondents citing each theme varied considerably among the three major respondent profession types (clinicians, social service providers, and researchers) and by

whether or not the respondent had personal experience with epilepsy, defined as a respondent who volunteered that he or she has epilepsy or has a child or other close family member with epilepsy. A chi-square test of homogeneity compared the groups to see if the proportion of respondents who mentioned a particular response differed by profession or by whether or not they had personal experience with epilepsy. Responses that differed significantly ($p < 0.05$) are reported in *Appendix B*; the appendix also contains tables of the top five most frequently mentioned response themes, by respondent type.

About the Respondents

The 101 individuals interviewed were classified in one or more of the following categories: clinicians (41), social service providers (41), researchers (19), and other (3). 14% of respondents work in the field of mental health.

Of the 41 clinicians interviewed, 15 were neurologists (including several epileptologists at epilepsy clinics) and 14 were nurses (including nurse practitioners and clinical nurse specialists). Other professions of participating clinicians included a social worker, a physician assistant, psychologists, neuropsychiatrists, and clinical coordinators.

Of the 41 social service providers interviewed, 28 work at one of the Epilepsy Foundation of America's affiliates. Other organizations included are Epilepsy Action (United Kingdom and Australia), the Epilepsy Foundation of America, the Abilities Network, the International Dravet Syndrome Epilepsy Action League, People Incorporated, Epilepsy Associations, Epilepsy International, and the Arc. Positions of those interviewed included 14 Executive Directors, several program directors and managers, educators, counselors, and coordinators.

The 19 researchers were primarily professors at universities in behavioral sciences, health promotion and prevention, clinical neuropsychology, medical sociology, nursing, and neurology. A few researchers worked for nonprofit organizations. Eight of the researchers also participated in a separate interview to provide details on an evaluated epilepsy self management program with which they were or are involved; findings from these interviews will be presented in a separate report. The three participants in the "other" category included a program manager at an epilepsy clinic, a public health advisor, and a co-developer of an online self management tool for people with epilepsy.

Towards the start of the interview, respondents were asked to provide "some background about your experience with or knowledge of epilepsy self management." The intent of the question was to learn about the respondent's professional background with epilepsy, but nearly a third of respondents volunteered their personal experiences as well. Eighteen respondents have or had epilepsy, and sixteen had a child or, in a few cases, another family member with epilepsy. A few had epilepsy themselves as well as a family member with the disorder.

Many respondents (82) also volunteered the number of years worked in epilepsy, and years of experience ranged from 1-44 years, with an average of 16 years. Only a few respondents volunteered more specific information about the people they worked with, but it was clear there was a mix of respondents in terms of ages served; some worked exclusively with children with epilepsy and their families, some with only adults, and some worked with both. In addition, a few respondents specified that they worked with children with Dravet Syndrome, people with disabilities, and those with dual diagnoses.

The majority of respondents were female (71%) and Caucasian/white (95%). Only 3% identified as Latino/Hispanic. Respondents resided across the United States and internationally with the following distribution according to region: Southeast (27), Midwest (27), Northeast (21), Southwest (11), West (10), and other countries (5).

About the Report Format

Findings are presented question-by-question. For each question, themes are described in descending order of frequency, with the theme cited by the largest number of participants described first. Each thematic header is followed by a number in parentheses; this number represents the number of respondents whose answer fell into that theme. At the end of the response summaries for most questions, there is a list of other less common responses with a number indicating how many individuals cited each response. Respondents often gave answers that were categorized into multiple themes.

Most Significant Challenge in Self Management

1. What would you say is the most significant challenge people with epilepsy face in managing their condition?

Note: to learn how the most frequently mentioned responses to this question differed by respondent profession type (clinician, social service provider, and researcher) and by whether or not the respondents have personal experience with epilepsy, see Appendix B.

Clinical Care (45)

Nearly half of the respondents identified the difficulty of finding effective and accessible clinical care as the most significant challenge people with epilepsy face in managing their condition. The most common challenge cited within this theme was that of attaining the best medications with the fewest serious side effects. Care often involves a trial-and-error process to find the best treatment or medication, and the process can be difficult and frustrating.

One respondent discussed how seriously side effects of anti-epileptic drugs can impact a person's life:

"I have seen people's lives change as they have shifted from high side effect medications to low side effect medications, and socially, and vocationally, everything got better as their side effects decreased."

This respondent also elaborated on another frequently cited challenge related to clinical care.

"For people who have ongoing seizures, [the most significant challenge] is access to healthcare; medication and treatment, there are so many without adequate healthcare that simply are continuing to bounce from emergency room to the street, or are being treated by physicians who are not specialized in epilepsy, that I think getting seizure control can be very difficult in those situations."

*-Program Director for people with epilepsy and mental health services;
person with epilepsy*

Other identified challenges related to clinical care include getting a timely, proper diagnosis; finding and accessing a neurologist with experience treating epilepsy; receiving optimum medical management; ineffective patient-provider communication; and receiving comprehensive care, that, for example, includes lab tests and psychosocial care and assistance.

"Many, many people with epilepsy never even get access to specialists in epilepsy, so if they don't have the medical specialists, they're not going to be getting the appropriate

content about what their epilepsy is and then they certainly won't get access to nurses or educators or anyone who could help them learn how to manage it. So it's a disconnect to begin with, about what their needs are, who they see, and that results in misinformation and a lack of access."

-Epilepsy Nurse Specialist; Research Specialist; person with epilepsy

"Very often I talk to patients who say... [the doctor] used this big word to describe it, and they don't know what the word means, they say I have partial complex seizures, but they don't know what that means, and without the knowledge of understanding that, it is confusing to listen to a doctor say this is what's happening, they have no memory of the event, and this is why you have to take medicine, and medicine isn't explained, medication isn't explained very well."

--Educator and Counselor, Epilepsy Foundation affiliate

Psychological Effects (26)

About a quarter of respondents discussed the significance of emotional challenges that come with having epilepsy. Most commonly cited was the fear or anxiety of waiting for the next seizure. This fear can prevent people from becoming fulfilled, productive members of society. Learning to accept that a person has epilepsy can also be a significant challenge, particularly among the newly diagnosed.

"Newly diagnosed patients, in many cases they don't recognized what's happened to them because they 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."

- Epileptologist and Director of Epilepsy Center

Discussed, too, was how the stigma of epilepsy can negatively affect a person's ability to come to grips with the disorder. One respondent mentioned how difficult it can be to accept the chronicity of a condition like epilepsy.

Several respondents cited depression and hopelessness as significant challenges for people with epilepsy. Cognitive challenges, stigma, neurochemical effects of epilepsy, and the unpredictability of seizures can trigger or increase the severity of depression. Self esteem and the possible loss of independence may influence depression as well. This mental condition, in turn, affects people's ability and motivation to seek out information, advocate for themselves, and in general manage their disorder as effectively as possible.

"Depression and a cycle of hopelessness, and not being able to see entirely a reason, kind of giving up because it doesn't seem to matter, that their quality of life doesn't seem to improve that much."

*-Staff Psychologist for social service agency for people with epilepsy;
parent of a child with epilepsy*

Stigma & Lack of Public Understanding (20)

Twenty percent of respondents indicated that potential and actual instances of stigma and its effects on a person with epilepsy were a significant challenge, particularly for children and teens.

“For youth... fear of having a seizure in public is huge for them... it’s a social issue, and the stigma’s huge for them.”

-Staff, Epilepsy Foundation of America

“The kids are treated differently by their peers, differently by community at large, and by doing that they have a lack of self esteem and if you don’t have any self esteem then you’re not going to be able to do... any self management.”

*-Registered Nurse working at a health plan;
spouse has epilepsy*

One respondent, however, saw a positive generational difference in regards to stigma:

“When I go out to schools, when I’m dealing with elementary school kids and all, especially in the rural areas, small towns, the kids are not fazed by the seizures as much as the adults. In other words, they know Johnny has had asthma, and if Johnny has an asthma attack, he does the inhaler, and he’ll be fine in a little while. They’ve known that Tommy has seizures, and they know the basic first aid, and they know he’ll be okay in a few minutes, and, you know, it, it really honestly seems to be that the next generation doesn’t attach nearly as much stigma, as say preceding generations, so I do kind of see that as a, a good change, in how seizures are being seen.”

-Director of Education and Client Services, Epilepsy Foundation affiliate

Others described adults with epilepsy who sought out information about their disorder but refused to participate in group education formats in which it would be apparent that they have the disorder. Several respondents connected the stigma and lack of understanding in society to problems with under- and unemployment.

Several respondents stated that the public’s lack of understanding of what epilepsy is poses a major challenge that can affect relationships, decisions to disclose their disorder to others, schooling, and employment. Those who witness a seizure but lack understanding of what it is may have an inappropriate and fearful response to the seizure, when ideally they would be able to proceed with helpful first aid.

“People in general, the public that I meet, have an idea that epilepsy means grand mal seizure, you fall down, you have convulsions, that’s it, so, and that’s not the most common form of epilepsy, by far... they have odd symptoms like partial complex

seizures where they will appear to be mentally ill, intoxicated, etc. when actually they are having seizures...”

-Educator and Counselor, Epilepsy Foundation affiliate

Affording medications (15)

A challenge cited frequently by respondents was the ability to pay for medications. Anti-epileptic medications can be very expensive for those without good prescription insurance coverage. Given that people with epilepsy can have trouble finding and maintaining employment—and health insurance is often tied to employment—this is a significant issue, one that has worsened in the recent tough economic times.

“In this economic climate that we have right now 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?’”

-Executive Director of an Epilepsy Foundation affiliate; person with epilepsy

In response to this challenge, there are numerous paths to take, none of which are ideal. Physicians may prescribe less expensive drugs that are either less effective or cause more side effects, or people with epilepsy may resort to skipping dosages and living with the breakthrough seizures that result.

“And with the cost of epilepsy medications, I think there are a lot of people with epilepsy who are skipping drugs, or who are breaking pills and taking part of their medication, and they are not taking it all, and they are having a few seizures, living with seizures, not telling doctors that they are having seizures, maybe even driving in that situation, and this impacts on their work, and on everything else, just because they don’t have good insurance to pay for things, I don’t know to what extent how that really plays out, because people aren’t always honest about it.”

*-Information and Referral Coordinator for an Epilepsy Foundation affiliate;
person with epilepsy*

Another significant issue raised by several respondents is that of drug switching. Many insurance companies will only cover certain versions of a drug.

“While there are generic anti-seizure medications, they aren’t always the exact same formulation. What may work with – or for a specific generic they work – a brand name or one of the other generics will not work, and a lot of people aren’t given the option of being able to get the type because there are so many different generic versions of the drug... for example, I’ve had to do battle with, personally, with my health insurance company, prove to them I need the specific one, instead of them telling me, well, you should take a similar version of it.”

-Epilepsy Services Coordinator for an Epilepsy Foundation affiliate;

Employment (15)

About fifteen percent of respondents said that employment is a great challenge; many people with epilepsy have trouble finding and keeping work. Inability to drive or secure reliable transportation often limits employability. Some have cognitive difficulties and other comorbidities that reduce or limit their work options, while others face discrimination from employers. Many fear losing their job as a result of seizures.

“I’ve worked with a number of people for whom, they’ve had seizures at work and in spite of all the ADA stuff, you know, employers often find a way around that, those restrictions, and the person finds themselves out of a job. Repeatedly.”

-Clinical Psychologist; Neuropsychologist

Respondents emphasized the interconnectedness of under- or unemployment with poverty, social isolation, mood disorders, reduced access to care, and inability to pay for treatments.

Compliance with or Adherence to Medical Regimen (14)

Another frequently cited challenge for people with epilepsy was compliance with or adherence to the prescribed medical regimen. In addition to financial challenges of obtaining the optimal medications as described above, complacency may also affect a person’s adherence; if the medications are effective and seizure control is achieved, the person may feel healthy and begin to skip medication dosages. Adherence may also be a challenge due to the significant side effects antiepileptic drugs can cause, including problems with memory, understanding and concentration. Many respondents discussed how cognitive difficulties that are common among people with epilepsy, stemming from both the medications and epilepsy itself, make it hard to follow directions and remember to take medications.

“Our patients have, particularly people who have chronic epilepsy... they have cognitive deficits which make it very difficult for them to understand directions and/or to follow directions and also because of memory, memory having been affected by chronic seizures and/or medicines, remembering what to do and when to do it, even with best intention can be very difficult.”

-Clinical Nurse Specialist in epilepsy program

Cognitive Difficulties (13)

Several respondents identified cognitive difficulties as the greatest challenge faced by people with epilepsy. In addition to the barriers to medical regimen adherence—and thus seizure control—cognitive difficulties can affect relationships, education, and employment.

“Often people have a lot of difficulty at school because they were having seizures growing up; they were often heavily medicated and some of them really don’t have a very good basic education because of that, because of the impairments of the epilepsy, and many of the medications also tend to make people very drowsy and sleepy and it’s hard for them to retain information.”

-Nurse Practitioner, Neurology

“People that have epilepsy often have specific cognitive problems related to the same damage in the brain that’s causing the epilepsy, which makes it very difficult to be fully oriented all the time and have normal, completely normal memory, and so I would say cognitive is a huge factor.”

-Physician of patients with epilepsy

Understanding their Disorder (13)

The importance of people with epilepsy being able to understand their disorder was stressed by several respondents as the most significant challenge. Given the wide spectrum of disorders that are labeled as epilepsy or occur alongside epilepsy, patients need to understand the specifics of their own individual diagnosis, including seizure types, seizure precipitants or triggers, the fact that it is a chronic condition requiring lifelong management, and how the disorder affects or may affect their lives. Reported related challenges included understanding treatment options, being aware of the resources available to them, and the role knowledge plays in taking ownership of their disorder and its management.

“Epilepsy is such a heterogeneous collection. All the different syndromes and individual seizure types, etcetera, so to understand that, or to get some kind of a manageable grasp on what that is, I think has to happen first before being able to say, or at least to begin to say, ‘what are the effects on me?’”

-Clinical Nurse Specialist

The Unpredictability of Seizures (12)

More than ten percent of respondents thought the greatest challenge faced by people with epilepsy was the unpredictability of seizures. This unpredictability may be a source of fear and stress, and it can limit a person’s ability to plan for the future, both short and long-term.

“I know with my daughter when she was younger, I used to make sure I was up and ready to go early because I never knew if we were going to end up in the ER or if we were going to be home that day.”

-Coordinator for an Epilepsy Foundation affiliate

“Even for myself, being controlled for so many years, it’s always still in the back of my

mind of it could happen, and, and how is that going to change my life, what is going to be, you know, different. And for individuals who have a harder time controlling their seizures, that's a very real problem that they have, is being able to manage that fear."

-Executive Director of an Epilepsy Foundation affiliate

Unpredictability, or the fact that a person with epilepsy can never be completely in control, can affect the person's sense of self-efficacy and thus their ability or motivation to manage their disorder. The lack of control can also affect a person's self-esteem.

"Some people, they believe they have no control because they have epilepsy. And as any therapist will tell you, 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's really magnified, so they would just sort of give up, you know, 'There's nothing I can do, I can't work, I can't ride the buses, I shouldn't cook.'"

-Executive Director of a social service agency for people with disabilities; person with epilepsy

Gaining Seizure Control (12)

The struggle to gain seizure control, especially among those with intractable epilepsy, was cited by more than ten percent of respondents as the most significant challenge for people with epilepsy.

"For people with intractable epilepsy, where the treatment itself is not effective, they are dealing with the condition at its worst because seizures are not controlled and there are many challenges that result – everything is harder. For them, the biggest challenge is improving seizure control despite a lack of prior success."

-Education Director of an Epilepsy Foundation affiliate

Some respondents also discussed the many factors that affect a person's ability to obtain seizure control.

"Most challenging, I would have to say that probably getting that seizure control, and that would entail communication with their neurologist, and finding the right treatment for their condition, after that it would be, once achieved seizure control, its maintaining, remembering to take medications, and also having systems in place to afford the different treatments, whether it's surgeries, vagus nerve stimulators, medications, diets, but being able to afford those types of treatments through acquisition of health insurance and benefits to allow that to happen."

*-Community Educator of an Epilepsy Foundation affiliate;
person with epilepsy*

Answer Depends on Various Factors (8)

Less than ten percent of respondents indicated that there is no single answer for such a broad question. The answer depends on factors such as time since diagnosis, type of seizure, whether or not the seizures are controlled, frequency of seizures, the side effects of the treatments, the comorbidities a person may have, and the age or life stage of the person with epilepsy. One respondent made this point succinctly, saying, “as if they’re all alike.” Another respondent pointed out how looking for global challenges and solutions is a weakness in the work of epilepsy self management:

“My observation and experience is that it’s not a one size fits all approach with people that have epilepsy.... I think this applies to self management as well, and perhaps most to self management because self management requires elements of diagnosis and treatment and combinations of lifestyle, so it really encompasses much more of the individual than any specific aspect of epilepsy, and so, you know, approaches that I’ve heard of or seen to teaching the, engaging a patient in the process of self management or the specific tools and approaches to it, have tended to not individualize the approach to specific people and are therefore less likely overall to be effective.”

-Neurologist; Professor of Neurology

Other themes (1-5)

Making lifestyle adjustments was a challenge singled out by a handful of respondents. They mentioned reducing stress, getting enough sleep, following a diet and exercise regimen, and changing what they do for safety reasons. Since people who have had seizures are typically not legally allowed to drive for a number of months, transportation was cited as a significant obstacle, especially in rural areas. Even if public transportation is available, the challenge can affect many other areas of a person’s life:

“It just keeps rolling and rolling and getting bigger and bigger, and just becomes such a huge problem that it affects everything else, from their social life to their work life, to everything else, and instead of spending ten minutes to get from here to there, they are spending an hour to get from here to there, and you do that twice a day or whatever, and a big chunk of the day is just eaten up just getting here to there, and they can’t get anything done other than eat, sleep, and work. This is not uncommon.”

*-Information and Referral Coordinator of an Epilepsy Foundation affiliate;
person with epilepsy*

A few respondents discussed how epilepsy can impact family life and other relationships, identifying social isolation and fear of disclosure as common struggles. Respondents emphasized the fear and embarrassment of having seizures in public, reclusiveness, underemployment, and how such challenges faced by youth affect compliance.

“For youth I think the biggest challenge they face is just social isolation, being afraid to disclose, having a very close network of peers that they will confide in, fear of having a seizure in public is huge for them, and compliance is a big issue for teens, because they don’t want to take the medications.”

-Staff; Epilepsy Foundation of America

Two respondents discussed reproductive challenges such as the effects of medication on birth control pills in young women and the many questions surrounding family planning:

“Women with epilepsy who are of, of child bearing potential and are thinking about, or they’re planning on becoming pregnant imminently, I think they have a lot of questions about... what will be safe for their baby.”

-Clinical lecturer, Neurology

Most Important Thing Person with Epilepsy Needs to Do

2. *What is the most important thing a person with epilepsy needs to be able to do to manage his or her condition?*

Note: to learn how the most frequently mentioned responses to this question differed by respondent profession type (clinician, social service provider, and researcher) and by whether or not the respondents have personal experience with epilepsy, see Appendix B.

Be Compliant/Adherent to Medication (32)

Nearly a third of respondents said that taking medications as prescribed was the most important thing a person with epilepsy needs to be able to do to manage the condition. They also discussed the many factors involved in adhering to a treatment plan, from accessing health care, being able to afford medications, understanding why it is necessary to take medication consistently and on time, to remembering to take the medicines.

“Being able to take your medicines I think would be very, very important... being able to take your medicine means being able to buy them, knowing and remembering that, to actually pop them in your mouth. You know, if you’re having a seizure you may forget, I mean it’s just, multiple levels. So being able to take your medicines is probably the most important thing, but it’s, it can be, there’s a lot of particular reasons why you may not be able to take your medicines.”

-Physician of patients with epilepsy

Understand their Disorder (31)

Almost another third of respondents stated that a patient’s understanding of his or her epilepsy is necessary to managing the condition. Many talked about the importance of understanding a specific diagnosis in terms of type of epilepsy, type of seizures experienced, that it is a chronic condition, what seizures are exactly, the risks of seizures, how medication blood levels affect the disorder, and what the person can and cannot do in terms of self management and safety. In short, people need to know what they are dealing with, and the more knowledge they have, the more effective their self management will be.

“One of the things that I am properly disappointed at and amazed by, is the lack of knowledge that people have about their own condition. I’ve published a number of papers in this area, basically as the result of surveys I have done, where I have found a significant proportion of people do not have that basic information about their epilepsy, and what I mean about basic information, if I was facing a patient in front of me, I would like to know by the end of any particular treatment program is that they understand

what epilepsy is, they understand about the type of epilepsy they have, they understand about why they take anti-epilepsy drugs, they have a basic understanding about the importance of adherence, they have a better understanding about triggers that might increase the probability of having a seizure, and in that respect I am talking about lifestyle issues, you know, the importance of getting good sleep, the importance of trying to keep stress to a minimum, the importance of their exercise, the importance of maintaining good emotional health, the importance of maintaining good social support, the importance of understanding the support of their families.”

-Professor of Clinical Neuropsychology

Some respondents stressed the need for people with epilepsy to have a deep understanding of how the disorder affects them individually, because an essential part of self management—thought by some to be just as or more important than medication compliance—is for patients to get to know themselves and become familiar with the signals their body gives them.

“To be in touch with how the seizure condition manifests for themselves personally. We have lot of information about averages and generalities, you know, if you take your medications your seizures will be fewer or you won’t have seizures or you’ll be able to eliminate them, but that doesn’t always work for everybody.”

-Professor, Behavioral Sciences and Health Education

Accept the Disorder (14)

Several respondents said that what people with epilepsy need to be able to do to manage their condition is come to terms with the realities of having epilepsy, accepting that they may not be able to completely control seizures and instead focus on what they do have control over—namely, being comfortable with the disorder and not being ashamed to tell others.

“Accept that part of who they are, and, and embrace it... to get past the classic denial stage—it’s not me, it’s not my situation. But to really incorporate that into their self image and their self concept, I think that is probably the most important thing a person with epilepsy needs to be able to do.”

-Clinical Nurse Specialist

Have a Good Relationship and Communication with Physician (14)

About fifteen percent of respondents emphasized the need for patients to have a good relationship with their physicians using open, effective communication so that together they can work towards good seizure control and address quality of life issues. Some discussed the need for patient and physician to work together as a team, with the patient taking a very active role, while others emphasized the need of patients to understand their rights and seek out a new physician if the relationship is not beneficial.

“They really need to have a trusting relationship with their health care providers to discuss some of the quality of life concerns that they might have.”

-Advisor for government agency; family member with epilepsy

“A lot of people are afraid of the white coat, the white coat knows what to do, they say do this, but they won’t ask, and then when they leave, they have all these questions, and they are not sure, so I think it is lack of ability to communicate effectively with doctors.”

-Educator and Counselor, Epilepsy Foundation affiliate

Have Access to Medication or other Treatments (13)

Several answers discussed the need to afford and access what are often incredibly expensive medications or other appropriate treatments. Some added that this access needs to be constant without any lapses, and that some people who do not have insurance can still get assistance to pay for their medications, but they need to plan well in advance in order to prevent any gaps in access.

Understand and Avoid their Triggers (13)

Several respondents pointed out the need to understand and avoid common triggers as well as triggers specific to individuals that may cause the onset of seizures. One respondent, for example, pointed out that for some, certain video games can trigger seizures. Many cited the importance of sleep, good nutrition, regular exercise, minimal amounts of stress, and avoiding alcohol. It is important for individuals to develop an awareness of their unique triggers in order to gain some measure of control over the seizures and an understanding of their particular condition.

Be a Self Advocate (9)

A number of respondents referred to the need to be strong self advocates, not only in seeking out medical care and services and being able to effectively communicate concerns, but in other areas such as researching information on the Internet, obtaining disability benefits and assistance, finding and maintaining employment and knowing their rights in the workplace, and other support services.

“They need to be able to be really strong self advocates, and have the skills to reach out into a variety of different disciplines, to get help, you know, not just not the medical community, they need access to physicians, pharmacists, other kinds of support services, employment services, and those skills to be able to reach out to folks and to

kind of be able to put all of it together, to be able to get all of the supplemental support to get the treatments they need to allow them to manage their condition.”

- Director of an Epilepsy Foundation affiliate

In recognition of the wide spectrum of epilepsy disorders and ages of people with epilepsy, one respondent added the caveat that not all people with epilepsy are capable of acting as self advocate, in which case a family member or other support person would need to advocate for them.

Participate in Treatment Process (9)

Almost ten percent of answers related to the need to actively participate in the treatment process. This relates to several other common answers, including being a self advocate, understanding their own individual disorders, adhering to their treatment plan, discovering empowerment, identifying and avoiding triggers, and having a good relationship and communication with the physician.

“They need to be able to ask good questions.”

-Executive Director of an Epilepsy Foundation affiliate

“I tell my patients all the time, for example, they have to tell me that there’s an issue because I can’t assume that there is. So they have to really take the lead in their own treatment, or their families have to take the lead if the patients themselves are not capable of doing that. So, that if there are, for example, problems with seizures, then they have to know that, if there are problems with side effects the treated, treating people have to know that. Otherwise we live in ignorant bliss and think that everything’s going okay.”

-Epileptologist; Director of Comprehensive Epilepsy Program

Have Social Support (7)

People with epilepsy need a strong social support network that understands their condition and can help them manage the disorder and cope with the ensuing challenges. This can be difficult due to the isolation that often results among people with epilepsy, but people can better manage with good emotional and practical support from others. Additionally, peers and others who interact with the person with epilepsy need to know about their disorder and the safety measures needed to prevent or respond to a seizure.

“While educating the patient I always encourage them to bring family members, spouses, parents, you know, depending on the circumstances, because I personally find that the more loved ones, the more caregivers are involved in the management, the better the person will do.”

-MD; Director of Hospital Epilepsy Center; President of Neurological Clinic

Other (5 or less)

- no one answer—it is a combination of interrelated things (5)
- have access to needed resources (5)
- have a good healthcare plan (5)
- understand safety measures (5)
- see a physician with expertise in epilepsy (5)
- be empowered (4)
- understand the treatment options (4)
- be oriented to achieve best health possible (3)
- keep diary of medical history (3)
- know when to disclose their disorder (3)
- maintain decent mental health (3)
- understand what self management is (3)
- have a resource person (2)
- have a good proactive physician (2)
- be able to negotiate social world (1)
- communicate effectively with others (1)
- have self-esteem (1)
- have a sense of humor (1)
- put disorder in context of their lives and approach it holistically (1)
- practice individualized problem solving (1)
- maintain independence when possible (1)
- seek medical care regularly (1)
- stick to a routine (1)

People with Epilepsy Most in Need of an Intervention

3. Among people with epilepsy, what subgroup of people are most in need of an intervention to promote self management?

CONSIDER: patient with disease/caregiver; gender; age; income; education level; race/ethnicity; rural/sub/urban; seizure frequency and type; presence of co-morbid conditions

People with Comorbidities including Developmental Disabilities (23)

Almost twenty five percent of respondents identified people with comorbidities—primarily mood and cognitive disorders—as the subgroup of people most in need of an intervention to promote self management. Answers suggested that this subgroup faces particular challenges since they not only have to deal with other conditions on top of their epilepsy, but also need to find good and affordable care for their entire spectrum of disorders.

“Every challenge that epilepsy provides, [for example] employment, if you layer on anxiety and depression on top of that it is exponential, and service providers for other co-morbidities for epilepsy, like brain injury, they exist, developmental disability and epilepsy, they exist, but there is a significant group in the middle who, I just think medical providers, are a little bit, very frightened, of screening for mental health because then they have to deal with it.”

*-Program Director for people with epilepsy and mental health services;
person with epilepsy*

“If you can manage to deal with the depression, you can do a lot for them even if the seizure control doesn’t necessarily get much better.”

-Professor of Medical Sociology

“The groups that we come across are the kids who are not well controlled on their medications and may have other medical conditions in addition to their child seizure disorder and they are, it’s just so challenging for them to do the self management because of their incredible diverse needs and ever-changing medications.”

-Program Administrator; public health systems

“Of all the clients, of all those 20 years, I would say that 90% had a combination, of you know, cognitive impairment, memory, and, you know, emotional issues, attached to their epilepsy, and they needed help with all of them, not some of them, but all of them to move forward. So some acknowledgement that you don’t just deal with seizures, epilepsy is more than just seizures, for most people I have ever met.”

-Program Director for people with epilepsy and mental health services;

People with developmental disabilities or cognitive challenges were often identified as a group in need of an intervention due to a lack of support services and resources, but some respondents expressed doubt about the ability to self manage among people with substantial challenges.

“I think those most in need, that probably would have the most difficulty self managing are people with developmental disabilities or psychiatric disorders, but I don’t know at what level they could ever be the self manager.”

-Public Health Nurse Consultant; State Department of Health

“I think the self management interventions are most powerful in patients who are cognitively able, who have some control over their potential psychological reactions to their condition.”

-Epileptologist

People with Intractable/Refractory Epilepsy (21)

About twenty percent of respondents cited that those who have intractable or refractory epilepsy as the subgroup most in need of a self management intervention. People with epilepsy who do not have good seizure control may be more likely to experience many challenges such as depression, memory problems, driving restrictions, stigma, and employment problems. Several respondents noted the high percentage of people with epilepsy who do not respond to antiepileptic drugs (AEDs).

“Patients who have seizures that occur more than at least every six months certainly have a more severe illness than those with rare, long past seizures.”

-Epileptologist

Others specifically discussed people with epilepsy whose seizures do not immediately come under control with the first medication prescribed and those who experience breakthrough seizures if doses are skipped.

“For the person who, you know, is lucky enough to have total seizure control with their first medicine, and on top of that maybe even if they skip a dose or two or a week or two, or, you know, no matter what their lifestyle indiscretions may be they don’t have recurrent seizures, you know, for them, what’s the motivation, you know, for self management. But for anyone else who’s not that lucky, I think it’s important.”

-Neurologist; Professor of Neurology

Lower Socio-economic Status (19)

Almost twenty percent of respondents identified people with less education and low income as those most in need of a self-management intervention. Those with low incomes often do not have access to appropriate care and may never see a specialist. Many cannot afford their medications, and they may skip or reduce doses to make the medication last longer. Some people miss or skip doctor appointments because they can't afford to pay for the gas.

Respondents discussed how people with less formal education may have trouble understanding their condition and how to manage, and may not be skillful at seeking out information, using it, and advocating for oneself.

“I think that the lower income and more uneducated people simply because they haven't learned how to advocate for themselves, and they don't know the system, so they don't know how to advocate, and how to work the system, and how to stand up for themselves.”

-Educational Services Director of an Epilepsy Foundation affiliate

One response pointed out that people with epilepsy may be economically disadvantaged because their seizures weren't controlled well, leading to employment problems.

Certain Races, Ethnicities and Cultures (19)

Many respondents pointed to certain racial and ethnic groups as the subgroup most in need of a self-management intervention. Two reasons for this response were widely cited: language barriers and cultural beliefs. Of the racial and ethnic groups, Hispanics/Latinos were cited most often, perhaps because in addition to cultural differences, they comprise a significant proportion of the US population and language barriers are often an issue.

“I was just with a Hispanic family yesterday, and it's just--we were talking about the vagus nerve stimulator, and they said, 'Well, I don't want someone to be in my child's body.' There is such a cultural difference between it and...even though they love their children so much, they don't realize how important it is to take those medications every day at the same time. And no matter what I do to try to get through to them, I can't seem to get through to them because of the language barrier.”

*-County Coordinator for an Epilepsy Foundation affiliate;
parent of a child with epilepsy*

Other groups identified were African Americans, Somalis, Hmong, Native Americans, Chinese, and Vietnamese. When discussing cultural attitudes, respondents spoke of how epilepsy is perceived and understood in different ways; they spoke of myth, stigma, lack of understanding, and religious and spiritual beliefs such as demon possession.

Young Adults and Teens (14)

Teenagers and young adults were cited by about fifteen percent of respondents for a number of reasons: they need to learn to self manage optimally so that they can live the many remaining years of their lives with a better quality of life; they are more vulnerable to stigma and the fear of being labeled; they tend to be more cavalier about their health and are therefore more likely to rebel against a treatment plan; and they tend to take risks and are more vulnerable to substance abuse. It was mentioned that teenage boys in particular tend to have a sense of invulnerability, so they are far more likely to resist adherence to a medication plan.

“Adolescence is when kids should become to be more independent with their epilepsy self management so that as adults they’re able to do that and already have a good, you know, past behavioral history of doing that. So I think that that is sort of, can be a preventative measure as well as an intervention for people who have specific needs at the moment, who are in that age range.”

-Professor of Nursing

“They’re not used to taking medications and they don’t like to take medications, you know it’s just a different mindset and because of how active they are and social stigma that they don’t want to be labeled. In my opinion, they tend to resist treatment more than anybody else.”

*-MD; Director of Hospital Epilepsy Center;
President of Neurological Clinic*

Parents and Caregivers (11)

More than ten percent of respondents stressed that parents and other caregivers are an oft-overlooked subgroup most in need of an intervention about self-management. These interventions could be especially important in cases where the person with epilepsy is either too young or too severely afflicted to take on their own self-management. Additionally, teaching parents and caregivers how to best facilitate self management can also help a person with epilepsy develop the skills and mindset to self-manage on their own in the future.

“I think parents are one of the most important people to really kind of teach the concept of self management because I think if they can get it and accept it, they could pass it to their children... I think if the parent believes they can handle it, then they can pass that confidence on to their child.”

*-Clinical Coordinator of a Comprehensive Epilepsy Program at a
Children’s Hospital*

On a similar note, some respondents discussed the need to include parents in order to correct or prevent detrimental approaches to disease management that grow from fear for the person with epilepsy.

“Caregivers and family systems too often organize around seizures in a maladaptive way, in which their fear for the family member will get them to start, you know, to set restrictions on the patient’s independence. Even, again, kind of limiting activities where the person would be safe... it’s an unholy alliance is what happens. I mean, family members don’t intend for this, it’s not like they’re consciously saying I want my son, daughter, family member to be dependent on me. It’s not that.”

-Clinical Psychologist; Neuropsychologist

This theme was discussed in depth in response to question 6 in which respondents were asked if there were others, aside from people with epilepsy and clinicians, who should be targeted in an epilepsy self management intervention; please see that section of the report for a more detailed discussion.

Trouble Choosing One Group (10)

Several respondents had trouble choosing any, or just one, subgroup of people with epilepsy that needed it more than others. Some said virtually everyone would benefit from a self-management intervention, while others believed there is no easy answer as there are so many different ways to cut the groups, adding that an answer depended on the desired outcomes of such an intervention. Some stated that it is not safe to generalize on a topic like this, and a handful of respondents pointed out that we don’t know enough about how socioeconomic status relates to need when it comes to implementing self-management programs.

“We have to look at what interventions we can do for the people with epilepsy who are in different groups, I think we have to be really careful about that and not say that one group is more important than another.”

-Pediatric Nurse Practitioner

One researcher referred to his research about this very question:

“Well, this is really tough for me to answer because this is one of the objectives of our research and we were, specifically have been looking at subgroups related to race, ethnicity, and socioeconomic status, and we have so far in our research found some somewhat surprising results. So we, so suggesting that we really have to be quite careful about making assumptions here.”

-Health Care Researcher, Department of Management, Policy, and Community Health

People in Rural Areas (6)

Some respondents identified people living in rural areas as the subgroup that could most benefit from a self-management intervention, because of the challenge they often face when trying to access health care.

“They don’t have as much access to specialists as, say, people in more urban areas, where there are clinics that specialize in epilepsy or neurology.”

*-Staff at Abilities Network and Epilepsy affiliate;
person with epilepsy*

“They’re possibly getting their health care, you know, on a local level, and it may not be the specialized care that they really should be getting, but they’re growing up in a very rural area where you may have to drive three, four, five, maybe even six hours to get to an epilepsy center, and there may be neurologists closer, but they may not have, you know, the specific knowledge of epilepsy that one might need, especially if they’re having some difficulty in managing their seizure frequency.”

*-Executive Director of an Epilepsy Foundation affiliate;
person with epilepsy*

Other (1-5)

People with epilepsy who:

- Do not have insurance and/or have poor access to health care(5)
- Are newly diagnosed (4)
- are not compliant with treatment plan (4)
- do not have an advocate (3)
- are children (3)
- are seniors (3)
- are adults (2)
- are female (2)
- have occasional seizures (2)
- are isolated and have no social support (3)
- have suffered a traumatic brain injury (2)
- are able to self manage (2)
- are diagnosed with “benign” epilepsy syndromes (1)
- are most psychologically distressed about having epilepsy (1)
- have partial complex epilepsy (1)
- are psychologically stable (1)
- could easily identify and better manage triggers (1)
- are unemployed (1)

Greatest Difficulty Clinicians Face

4. What do you think is the greatest difficulty facing clinicians in helping their patients with epilepsy better manage their condition?

Note: to learn how the most frequently mentioned responses to this question differed by respondent profession type (clinician, social service provider, and researcher) and by whether or not the respondents have personal experience with epilepsy, see Appendix B.

Time Limitations (37)

Over a third of respondents identified insufficient time as a clinician's greatest difficulty in helping their patients with epilepsy better manage their condition. Respondents discussed how in today's healthcare environment, clinicians, and physicians in particular, have limited consultation times for each patient, they are overworked, and there is great pressure to move on to the next patient quickly. In addition to short consultation times, some respondents also mentioned how infrequently most people are able to visit the clinic. Clinicians don't have the time to educate patients on what is a fairly complex chronic disorder that often comes with comorbidities, or to get to know the patient and individualize the education and teach specific management skills. Nor do they often have time to find other resources they can share with their patients. Instead, clinicians generally focus on medical management, but do not discuss behavioral changes or counsel patients on how to deal with the consequences of having the disorder.

"So much time is taken up with an assessment of how the patient's doing, getting patient histories—have you had some break through seizures, etcetera, doing the labs, and then any changes that need made in the treatment, you know, and they need to explain that, so they don't really get into a lot of management."

-Director of Education and Client Services with an Epilepsy Foundation affiliate

"I think that the amount of time that, to be able to really understand and know the patient. I think that's, that's one of the greatest difficulties right now, is, is being able to develop a relationship with people, where you can get into things a little bit more. I think time constraints, financial constraints, the frequency of visits."

-Clinical Nurse Specialist

Limited Focus (25)

About twenty five percent of the answers identified the greatest challenge for clinicians as the approach taken primarily by physicians that does not seek to gain a holistic understanding of how epilepsy can impact a patient's life. Physicians are trained to diagnose and treat disease from a drug management point of view, and many are not equipped to address more holistic issues such as quality of life, psychological comorbidities, and effects of stigma. One respondent pointed to a lack of resources for physicians such as tools to assess the informational and educational needs of patients. Clearly, lack of time presents a barrier to this approach as well, especially given the complexity of epilepsy. They may focus only on seizure control and the clinical, quantitative presentation instead of really listening to and understanding a patient's experiences, perceptions and concerns in order to tailor treatment to their individual situation.

"I have found that certainly in the epilepsy community, physicians really need to communicate better with their patients, they need to be able to think a little more globally, and not focus on just the seizures, but beyond what's going on just inside the brain, think about the effects it is having on the rest of the person, whether that is comorbid conditions, social effects, and again they really need to be able to communicate and ask families, ask patients what their needs are beyond focusing on seizure control."

-Doctor of Medicine, private pediatric group; parent of child with epilepsy

One respondent stressed the importance of maintaining this holistic approach for even the less severe cases of epilepsy.

"They tend to think that people who have less severe epilepsy shouldn't be as concerned about things as people who have more severe epilepsy and sometimes those are the patients who are trying to have a normal sense of life and it makes it much harder for them... I think they see so much of it that they forget what a, how much of a big impact it can have on patients."

-Professor of Nursing

Finding the Best Course of Treatment (11)

While there are a number of medications and other treatment options for epilepsy, it can be a slow and frustrating process to find the treatment that works best, as more than ten percent of respondents pointed out. Clinicians face an even greater challenge with intractable cases, when no treatment is effective. This theme surfaced from among several answers, many of which referred to the emotional challenges faced by clinicians—frustration, a sense of helplessness—when no improvements result from treatment or there are setbacks such as intolerable medication side effects.

“There really is no panacea for epilepsy, there is no one thing that cures it all, and so I think that can be really difficult, because the patient can come in and expect the physician to know everything and say that here is your magic pill, and it doesn’t work like that.”

-Educational Services Director of an Epilepsy Foundation affiliate

Lack of Supportive Services (11)

Many answers pointed to a lack of supportive and complementary services for people with epilepsy as the greatest challenge for clinicians who are trying to help their patients. Respondents discussed different types of services outside of the clinical setting that are lacking or difficult to find, including counseling and other mental health resources, vocational assistance, transportation services, informational resources, and housing.

“It’s kind of hard to know where to go sometimes for things.”

-Nurse Practitioner, Neurology

Respondents also referred to the lack of services available in the clinic setting including sufficient staff to triage phone calls to answer patient questions about medications. A lack of an interdisciplinary approach was also cited.

“Most clinicians don’t have the benefit of working in a multi-disciplinary team that are experts in epilepsy; a particular gap is psychiatric resources... It really is a multi-disciplinary disease; it needs to be approached from an interdisciplinary angle.”

-Clinical Nurse Specialist; Clinical Director for Seizure Disorder Center

Patient does not Follow Care Plan (11)

Several respondents identified noncompliance, or nonadherence, as a major challenge. Respondents discussed working with patients who do not take charge of their lives, who are not willing to take responsibility, and who do not feel accountable for their noncompliance.

“At times there seems to be a lack of interest on the part of some patients, a sort of a deference to the family member or significant other as sort of the person that needs to kind of manage this for them, rather than the patient wanting to take responsibility.”

-Nurse Practitioner, Neurology

Some expressed frustration because of their inability to motivate patients and parents to recognize the importance of treatments, behavioral issues, and following their care plan. A few respondents also discussed challenges posed when patients are unable to attend follow-up visits due to transportation and financial issues.

Inaccurate Reporting from Patients (10)

Another challenge faced by clinicians, as identified by ten percent of respondents, was inaccurate reporting from patients that interferes with accurately identifying barriers and appropriate next steps. Many reasons for this were discussed: patients may be dishonest for fear of losing their driver's license; patients or parents don't report what they considered "non medical issues" such as their child's school performance; due to developmental delays or other cognitive impairments, they don't understand the disorder enough to report relevant issues; they forget how many seizures they have had; or they simply aren't aware when they have had seizures. One clinician lamented the fact that there is no clinical marker for seizure frequency.

"We don't have a marker that is independent of the person telling us that they had seizures or how many seizures they had. That is, I think, a huge limitation for clinicians... We don't have a CAT scan, we don't have, if this were diabetes we can do a hemoglobin A1C... if we had some way of measuring seizures, an objective measure of seizures, that would be, I think, that, that would be amazing..."

-Physician of patients with epilepsy

Access to Medications (10)

Several respondents identified access to medications, and the time and trouble required to obtain access, as a significant challenge for clinicians. Clinicians of patients with insurance find that insurance companies are limiting physician's choices for medication management, and oftentimes insurance will only cover a generic drug, or present imposing barriers to get more expensive drugs approved. Many anti-epileptic drugs are cost prohibitive for patients, and while there are assistance programs, the time required to find these programs and obtain their benefits is burdensome.

"[Having] them be able to afford their medicines or kind of jumping through all the paperwork hoops of getting them to be able to take the medicine that seems to work best for them is the biggest kind of hurdle at present."

-Clinical Lecturer, Neurology

Others (7 and under)

- Keeping up-to-date medically (7)
- Reimbursement for services (7)
- Clinicians not equipped to provide education for self management (6)
- Fragmented health care system and lack of care coordination (3)
- Clinicians not equipped to address comorbidities (3)
- Letting the patient lead a full life (3)

- Patient-provider communication (3)
- Comorbid complications (2)
- Family members who become obstacles to self management(2)
- Patients not referred to specialists (2)
- Difficult to diagnosis cases (1)
- Lack of epilepsy specialists (1)
- Low health literacy levels among patients (1)
- Paternalistic attitude of some clinicians (1)
- Stigma and lack of public awareness about epilepsy (1)

Clinicians Most in Need of an Intervention

5. What type of clinicians are most in need of an intervention to promote self management?

CONSIDER: profession, specialty, population clinician serves, years in practice

Specialist Physicians, Neurologists, Neurology Department (53)

More than half of the respondents cited specialist physicians, neurologists, and the neurology department as the type of clinician most in need of an intervention that would help them assist their patients in the task of self management. A common opinion was that because epilepsy patients only make up a small part of a given general neurologist's practice, they do not have as much experience or knowledge of epilepsy as might be desired.

"Number one that I came up with was neurologists who do not have an in depth knowledge of the disorder...the neurologists that, kind of, they treat migraine, they treat stroke, etcetera, but they don't have a whole in depth expertise in epilepsy, and you can't, you know, specialize in every brain disorder, and we understand that..."

-Director of Education and Client Services with an Epilepsy Foundation affiliate

General neurologists are not always as up to date as they could be—one respondent mentioned how difficult it would be to keep up with all the peer reviewed literature—or have enough resources to treat epilepsy. One concern is that neurologists focus on seizures when it comes to treating epilepsy and neglect other aspects of the condition because of the resources available to them and the lack of specialized knowledge they have of the disorder.

"Too many general neurologists are stuck on seizure frequency and severity as the only important clinical variables to track in their patients, and drugs or epilepsy surgery as the only forms of intervention with their patients that they can provide."

-Neurologist; Professor of Neurology

Another worry was that because neurologists are so busy, they can often be too hurried or rushed with their patients, leaving most of the communication up to their nurses or social workers. An intervention that would help neurologists to better communicate and educate their patients would be beneficial for both parties, especially because neurologists have a lot of "expert clout," as one respondent put it, and their opinions could greatly reinforce the advice and directions from nurses or others, if more time was set aside for doctors and patients to communicate.

“The neurologist I think brings into play the strength of being the, the medical expert, so I would argue that for them to be able to successfully conduct a brief self management intervention with a patient would go a long way in terms of its impact with the patient.”

- Professor, Center for Health Promotion and Prevention Research

Some thought that neurology departments as a whole would benefit from an intervention to promote self management, because patients often have to interact with everyone in the department, not just one specific person. Similarly, others mentioned that neurology in general could be more of a team player. Neurology plays a large role in epilepsy treatment, but it was suggested that there could be more referrals to organizations such as the Epilepsy Foundation, which are equipped to help patients in different ways.

“I really think the neurology community in general needs to broaden their perspective, really see themselves more as a team member with the patient, with the family, with the community.”

-Doctor of Medicine; parent of child with epilepsy

General practitioners, family doctors, primary care physicians (37)

A significant number of respondents cited general practitioners, family doctors, and/or primary care physicians as the type of clinician most in need of an intervention. Most epilepsy patients are treated by their primary care physicians, and many epilepsy patients get most of their medical information from their family doctors without ever, or only rarely, seeing a specialist. One common worry was that primary care physicians, trained to treat general conditions, have limited training or education in the specific treatment of epilepsy.

“When you look at epilepsy... seventy to eighty percent of those patients are never going to be seen in a comprehensive epilepsy center, so they’re missing out on a lot of opportunities, so I do think we need to make sure that [physicians] understand what is available to help them manage patients, manage epilepsy, and what’s available for patients with epilepsy to help them do the best they can.”

-Pediatric Nurse Practitioner

Another prevalent view is that general practitioners do not know when to refer their epilepsy patients to specialists or epilepsy centers. Referrals that should have been made much sooner end up taking a long time or do not occur at all, sometimes because general practitioners do not recognize if a patient is exhibiting a unusual seizure type.

“What are doctors supposed to do? Doctors are supposed to diagnose and treat. Most doctors don’t see themselves as educators and counselors...but they need to facilitate self management. So they’re a primary group to understand what self management is, to help facilitate it by referring people.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

“The guidelines need to be really specific at what point patients are referred, so there’s more of a partnership there between general practice and the epilepsy specialist... I think patients deserve at least to be evaluated at points in their lives by experts of epilepsy, because of the indications of... a long life of epilepsy, especially when they’re uncontrolled.”

-Clinical Nurse Specialist; Clinical Director for Seizure Disorder Center

However, the trend of infrequent patient referrals is also thought to occur because general practitioners cannot easily refer patients to specialists when there is a scarcity of specialists to begin with, and when the ones who are available are too time and cost prohibitive to patients—especially to those patients who live in rural areas away from any convenient epilepsy center, university medical center, or state of the art hospital.

“The family physicians that are in rural communities or community clinics where they really can’t say to the family, ‘just go talk to your specialist,’ because the specialist may be six hours away... In a way, they are forced to do a lot more intervention with kids with complex conditions, including epilepsy.”

-Program Administrator; public health system

Other reasons why general practitioners, family doctors, and primary care physicians were cited as most in need of an intervention to promote self management include the view that patients simply are not getting the most up to date treatments, will not have access to all the clinical trials and new medications about which a specialist could inform them, and their seizures may go undiagnosed, for as long as a year or more, all of which could contribute to decreased quality of life for the patient as well as insufficient care.

Nurses (28)

Many respondents suggested that because nurses see patients the most, and spend the most overall time with patients, they are the most appropriate choice for the type of clinician in need of an intervention to promote self management. Additionally cited as beneficial is their medical background, along with what one respondent called “a more holistic perspective.”

Because of the time nurses spend with patients, they are allowed the opportunity of better communication and a fuller knowledge of the entire life situation of their patients than other clinicians are able to have. Some mentioned that helping patients manage or live with their diseases is already part of a nurse’s job description, so further enabling them to do their jobs could be advantageous to both nurses and patients.

“The importance of [nurse educators] to be able to successfully motivate is sort of fundamental, because they arguably have the greater relationship with patients, so for them to be able to successfully empathize with [a] patient’s situation, acknowledge that,

and bring the patient on board to strategize and enact self management activities when they leave the clinic successfully is of paramount importance.”

-Professor, Center for Health Promotion and Prevention Research

It was suggested that nurses could also benefit from the intervention because they are the type of clinician patients have easiest access to. In rural areas especially, there might not always be a doctor readily available.

“There are a lot of nurses that are kind of the first and last... [Patients] may see a doctor once a year, but they will go to the county health center and see a nurse, maybe even, if they are lucky, a nurse practitioner.”

-Program Director of an Epilepsy Foundation affiliate; has family member with epilepsy

For some, the ideal nurse in this scenario would be one who has specialized in epilepsy, neurology, or neuroscience in order to ensure that their medical background is sufficient. Included in the responses most commonly were nurses, nurse practitioners, and nurses who specialized in epilepsy. Other categories included clinical nurse specialists, advanced practice nurses, nurse educators, school nurses, and others.

Mental Health Practitioners, Psychologists, Psychiatrists, Psychotherapists (17)

Because of the frequent occurrence of comorbid disorders in patients with epilepsy, mental health practitioners of all kinds are often considered essential to the treatment of epilepsy. Mood or mental disorders can be caused by side effects of medical treatment as well as the pressure of living with epilepsy.

“I think your psychologists because there are a tremendous amount of side effects that go with this and there is usually depression. There’s also other problems that come along with having epilepsy and having the drugs that they take.”

-Social Worker for an Epilepsy Foundation affiliate

Others noted that mental health practitioners are most in need of an intervention to promote self management because there is a widespread lack of knowledge about epilepsy in that field; very few mental health practitioners specialize in epilepsy, which makes some of them reluctant or even fearful to take on epilepsy patients, since they may not know what to expect from their patients or how to go about treating them.

Social Workers (13)

Social workers were chosen by about ten percent of the respondents as the type of clinician most in need of an intervention to help promote self management. Some reasons for the choice include how social workers can function as a mediator between doctors and patients, and how they can focus on other parts of a patient’s life that doctors, due to time constraints, have to

gloss over or don't address. They can educate patients about their disorder, refer them to other organizations or groups if necessary, and they generally have more time to spend with patients than doctors or nurses do. One respondent mentioned that social workers can often be helpful to patients with low income, since they can be used as a cheaper alternative to psychotherapy.

“Social worker education is unique and it really does take a whole person approach. That the person is not just their illness, is not just their medication...it's who they are, it's who their family is, it's what their goals are, it's what their social, their support network...it extends beyond the individual.”

-Clinical Social Worker in Neurology

Other (less than 10)

- ER and urgent care (7)
- Clinicians that treat patients in rural areas (5)
- Anyone dealing with epilepsy regularly (4)
- Case managers (2)
- Public health (1)
- Physician Assistants (1)
- Clinicians that treat low income populations (1)
- EEG technicians (1)
- Practices that emphasize high productivity (1)
- Surgeons (1)
- OBGYNs (1)
- Medical students (1)
- Home healthcare (1)
- Pediatricians (1)
- Pharmacists (1)

Others in Need of an Intervention

6. *Aside from people with epilepsy and clinicians, are there others who should be targeted in an intervention to improve self management of epilepsy? If so, please describe them.*

Family Members, Caregivers, and Friends (51)

Over half of the responses included the family, caregivers, and/or friends. Specific family members singled out were parents, spouses, siblings, partners, and significant others. Some regarded family as a broad, self-defined term that may include friends or anyone in the person's life who can provide frequent support. The resounding reason to include such people in an intervention had to do with promoting a supportive network that encourages effective self management. As one respondent explained, "they all need to be on the same page."

Family members can play a critical role in helping a person with epilepsy practice good self management skills. They can set the tone in the household and, in the case of young children with epilepsy, parents can instill the importance of self management in their children from an early age. Family members are affected by the disorder, and therefore may benefit from an intervention that reduces or prevents negative effects.

"It's very difficult to help the family dynamic survive epilepsy. Spouses can sometimes feel like a parent of a person with intractable epilepsy."

-Consumer Ombudsman, Inpatient Health Plan; person with epilepsy

Even as several respondents discussed family members as a natural choice of support, many others pointed out the potential for familial dynamics and baggage to interfere with self management efforts.

"I think family members are often very anxious about the way that the person, the way that the family member with epilepsy is behaving or what they're doing, they can impose restrictions that aren't necessary necessarily, they can sort of inhibit what the person's doing, so I think they need help, to see that a person can self manage..."

-Professor of Medical Sociology

Some respondents stressed concerns about familial over-protectiveness that can hamper self-management efforts. Such concerns were voiced as arguments as to why family members need to be included and as arguments as to why people with epilepsy should have the option to include friends rather than, or in addition to, family members in a program that promotes self management.

“Maybe having a good friend, that someone identifies and can be a good buddy so to speak, and help with medication reminders and other health-enhancing lifestyle behavior reminders, messages, those kind of messages coming from a more neutral friend might actually be more beneficial.”

-Advisor for government agency; has family member with epilepsy

School Personnel (47)

Nearly half of respondents discussed school personnel as a group that should be targeted; personnel identified included teachers and teacher aides, school health nurses, guidance counselors, social workers, therapists, and administrators. The most common reason for this choice was that school personnel need to be trained to react appropriately to seizures in the school system. Many teachers do not know how to react to a seizure, and children too often end up in the emergency room after the seizure is over and the ER staff can no longer do anything for the child. A few respondents brought up teachers’ reluctance to use Diastat, a rectally applied medication that can stop acute repetitive seizures, despite it being a potentially life-saving measure for the child.

“What I see most lacking, because I work with children, is the need for school nurses and other professionals within the school to have better understanding of epilepsy and its treatment and about how these children, you know, should be handled in terms of their seizures in the school setting.”

- Nurse Practitioner; Children’s Hospital

Another cited reason to include school personnel was so that teachers could recognize, and accommodate, learning impairments and behavioral issues in students that may be linked to epilepsy or side effects of their medication. For children who have very difficult to control syndromes with epilepsy, schools need to develop individual educational plans to increase the child’s ability to learn.

Involving school personnel may add to and improve the information a physician can use to help patients. One respondent discussed the work of a physician who trains the teachers of his patients to recognize their seizures, record them, and report them directly to him so that the physician can better manage the child’s disorder.

Involving school personnel may also provide an opportunity to educate classmates about epilepsy in order to remove some of the stigma and fear of seizures and provide a more accepting and supportive environment for the child.

“That also helps because a person having a seizure, or having epilepsy, is tough enough having the condition, but the social treatment, from the lack of understanding from fellow classmates can be to a very young person, can be just devastating.”

-Executive Director of an Epilepsy Foundation affiliate; parent of child with epilepsy

“It’s not just the teachers, it’s not just the school nurse, it’s hey, you know, you guys are out on the playground with this child, right, and let’s talk about the fact that this isn’t a contagious disease... they have some medicine just like a lot of you do for your, you know, asthma or whatever.”

- Professor; Center for Health Promotion and Prevention Research

School administrators were identified because as policy makers, they have influence on how the above issues are handled in the schools. To provide an example of an inappropriate policy, a respondent spoke of an instance where a child who experienced a seizure was instructed to stay home from school for two weeks.

It should be noted that one respondent was unsure if involving teachers would be an appropriate target, given their very heavy workload, and another adamantly stated that involving teachers would be a waste of time because they deal with too many disorders to focus on just one.

Employment, Employers and the Workplace (20)

A common theme among responses related to employment and the workplace. Several respondents identified employers and prospective employers as desired targets of a self management intervention. Also identified were employment agencies, fellow employees, human resources, and occupational nurses. Many respondents discussed the need for these individuals to better understand the disorder overall and know how to react to seizures, while others discussed the need for employers to know how to facilitate safety and self management.

“If someone falls and breaks, their arm’s in a sling, it’s easy for the human resources folks to see this person needs an accommodation, but people with epilepsy they look completely normal, and I feel like sometimes I get some pushback from employers giving accommodations to folks... I think there’s a need for education of the employment community about seizures that, you know, even though the person looks fine, there’s a risk.”

-MD; Director of Hospital Epilepsy Center; President of Neurological Clinic

One respondent described the need for employment agencies to learn to counsel people with epilepsy on appropriate jobs to seek that will not put them at risk and to learn how to address the issue of divulging one’s disorder. Disclosing that information can cause conflict; it is important to share so that others know what to do in case of seizures but there can also be a lot of pressure to hide one’s epilepsy in order to avoid discrimination and job loss.

Social Workers (14)

Social workers were identified by several respondents. Most did not explain their choice, perhaps because they were previously discussed in the preceding question about the type of clinician most in need of an intervention.

“Social workers... could use some education on helping to support people in making self management decisions... and it’s not that they have to do the self management, but helping to educate their clients on good self management tools, on resources in their area, and things like that.”

-Executive Director of an Epilepsy Foundation affiliate; person with epilepsy

Less Common Responses (10 and under)

- All professionals who interact with people with epilepsy (10)
- The public (10)
- Law enforcement (8)
- Staff in group homes and institutional care facilities (6)
- First responders (6)
- Mental health professionals (4)
- Epilepsy foundation staff and board members (3)
- Peers (3)
- Policy makers (2)
- Religious or spiritual leaders (2)
- Any agencies (1)
- Day care (1)
- Nursing homes (1)
- Pharmacists (1)
- Senior groups (1)

Agencies and Organizations to Manage Programs

7. What agency or organization should manage epilepsy self management programs?

Note: to learn how the most frequently mentioned responses to this question differed by respondent profession type (clinician, social service provider, and researcher) and by whether or not the respondents have personal experience with epilepsy, see Appendix B.

Epilepsy Foundation (65)

About sixty five percent of respondents said that the Epilepsy Foundation of America and its affiliates should manage epilepsy self management programs. Many of the responses mentioned that the Epilepsy Foundation was the best choice because of the affiliate network already in place across the country, and because it already directs similar programs. As one respondent pointed out, “the whole purpose [of the Epilepsy Foundation] is to have grassroots interaction with patients and family members.” For a variety of reasons, the Epilepsy Foundation was considered the organization best situated to provide education and advocacy for people with epilepsy and their support networks.

“The Epilepsy Foundation certainly seems well suited to deal with these issues. They have broad reach, they have a good understanding of the problem and they seem to be a go-to organization for a lot of people who are looking for answers.”

-Epileptologist; Director of Comprehensive Epilepsy Program

“[The Epilepsy Foundation] would be the group to do that because our primary focus is empowerment, teaching empowerment, self management, and becoming an effective partner in the health care chain.”

-Staff; Epilepsy Foundation of America

Respondents noted that the Epilepsy Foundation has resources that can cover a wide range of specific cases for individuals with epilepsy. One person brought up the important point that their local Epilepsy Foundation has “a huge library base of literature both in Spanish and English, so we refer a lot of patients to them to get a lot of the basic literature,” which is an invaluable resource for people with epilepsy who would otherwise be struggling with a language barrier.

Other respondents noted that self management programs could be implemented through the venue of the group meetings that the Epilepsy Foundation affiliates often offer. A few respondents mentioned that patient-run programs might prove effective, and if so, the Foundation would be a good choice to develop and oversee such a program.

“I think the Epilepsy Foundation, as a community organization, can bring all of those resources together under the same umbrella, to provide folks with what they need, to put together better self management training opportunities for patients.”

-Director of an Epilepsy Foundation affiliate

The Epilepsy Foundation is considered by many people a go-to organization for patient help, and most patrons of the Foundation come out of it with good experiences. However, a few problems were brought to light as a caveat to choosing the Epilepsy Foundation as the managing organization. The amount of work the Foundation does is already overwhelming, there is a lack of funding available to do more than is already being done, and although the affiliate network covers almost every state in the country, there are still many people who don't know about or have access to the organization. Many rural areas, especially, do not have a local affiliate close enough to make it a viable option.

“I don't know, I think it's a good role for the local Epilepsy Foundation, but...ours has been a very weak organization. They have suffered from losing funding, lack of funding, lack of personnel...”

-Clinical Nurse Specialist in Epilepsy Program

“The Epilepsy Foundation grew out of a direct service model, so service to people and families with epilepsy, as well as education, is its primary function, and then to a lesser degree, advocacy and research are part of the mission. I say to a lesser degree only because funding and advocacy for research are sort of separate pots of money for direct client service and public education fund.”

-Executive Director of an Epilepsy Foundation affiliate

Hospitals, Comprehensive Epilepsy Centers/Programs within Health Systems (40)

About forty percent of respondents said that hospitals, health systems, or comprehensive epilepsy centers or programs within health systems should manage epilepsy self management programs. High on the list of such programs would be clinics that specialize in neuroscience or epilepsy and that have a strong background or specialized training in human or social service.

These centers and health systems are a top pick because of the high number of patients that move through them. They are often the first place a person with epilepsy will go for information. Although time is usually very limited in these centers, they often have condensed information and materials on hand to share with patients. Several respondents pointed out that if epilepsy patients go to their doctor's office for self management, there will likely be a much higher compliance rate if self management discussions are planned for immediately before or after a scheduled doctor's appointment. Moreover, health systems are already staffed by medical professionals who have the clinical expertise that patients with epilepsy need.

“You need to have the medical expertise that can be brought to bear, you know, provide the information and expertise regarding whatever medications are needed, what other kinds of interventions might be available, such like a VNS or...surgery.”

Others mentioned that hospitals or university health systems are a good fit for administering self management programs because they are large enough that they see a heavy flow of patients, and they often have more resources available than smaller organizations or non-profits.

“The documentation process requirements for handling public funds often stresses the resources of a small organization—any non-profit—any organization that deals a lot with the government and with private foundations and has a large reach may have the infrastructure, and it wouldn’t take away from the other activities of the organization. Managing a federal grant or a large foundation grant is almost a job in itself, and in a small organization like the Epilepsy Foundation, that might fall to the same people trying to actually implement the process.”

-Consumer Ombudsman, Inpatient Health Plan; person with epilepsy

Many cited clinicians’ offices where there are adjunct staff for the specific task of imparting self management techniques to patients as a useful place to begin managing these programs. In this scenario, clinicians would not have to find the extra time in their already hectic day to facilitate self management, but for the person with epilepsy, their medical and self management care would still occur in one convenient place. Along with this, one respondent made the important point that within a health system, there is the right to communicate between health professionals. A neurologist can work in concert with, for example, a psychologist and primary care physician without being hindered by patient privacy laws, “because the patient would [be able to] sign off for the collaboration.”

Another respondent mentioned that self management programs should be filtered down through a health system.

“It’s got to start at the top, that the health insurer recognizes the importance of self management and has systems or resources or tools or web based or something that they are either giving to families directly via the web mail or the mail or they’re giving it to a provider for that child who then gives it to the family.”

-Program Administrator; public health systems

Government (20)

About twenty percent of respondents said the government should be in charge of managing epilepsy self management programs. Research oriented departments within the government have a lot of information about patient demographics that could be useful when organizing self management programs.

“I think when you have the health agencies that are trying to work with people, like social services, Department of Health and Human Services in the county, they know the

people who can come in; they know the people that need their help. They need to be educated; they need to help manage self management programs.”

-Social worker for an Epilepsy Foundation affiliate

One point that was raised was that government organizations are particularly useful for the lower socioeconomic segment of the population. County health clinics are often funded through the state, and they serve as the front lines to many people in rural and low-income areas. They are available to everyone, accessible to many, and often there is the option of government assistance for those in need.

Several respondents said that Center for Disease Control and Prevention (CDC) specifically plays an important role in epilepsy self management programs because of the interest it takes in chronic disease issues and the funding it provides for many research projects and programs.

“A lot of our original programming is grant funded through CDC... Just as an example, the school nurse training program...it’s a standardized program, was developed by CDC in conjunction with the National Association of School Nurses and the Epilepsy Foundation. They created a standardized program, a CME program for school nurses on epilepsy, and so a lot of times CDC will do the development of a program, typically there’s a two to three year funding program for us to implement the programs, then the programs kind of have to carry themselves. So I feel like the CDC, you know, aspect of it is very important, I mean, they design programs extremely well, so I think they’re important partners in all of this.”

-Director of Education and Client Services of an Epilepsy Foundation affiliate

Team Approach (19)

Most respondents who selected a team approach as the best option for managing epilepsy self management programs made their decision based on the idea that no one agency or organization has all the resources needed to fully address all the issues of epilepsy self management. Medical, education, and social service expertise, for example, can be found in various separate organizations that should work together to administer epilepsy self management.

“There are so few people that understand the intricacies of [epilepsy], that people can walk and talk while they are having a seizure and just act very strangely... Having a better understanding from more than one agency I think would be better...I think it needs to be a collaborative kind of effort, between teaching hospitals, clinicians, like neurologists, and social service educational type agencies.”

-Educator and Counselor, Epilepsy Foundation affiliate

Others saw the team approach as the only viable option because it presented an avenue for customization or individualization of a self management program for specific patients. Because epilepsy is a disorder that manifests itself differently in almost every person who has the

condition, each individual patient will have different needs that often have to be addressed in ways perhaps unlike any of his or her peers.

“There needs to be some options, you know, perhaps not having it housed in one individual agency or organization, but perhaps a spectrum, which would meet the needs of each patient.”

-Physician Assistant, Neurology

The issue of difficulty in navigating the system was also brought up. Respondents pointed out that although there are a lot of good organizations out there, they all eventually stop short in the services they provide, and patients have to rely on referrals to get to the next step. In a team approach to self management, various organizations with expertise in isolated areas can work together to make sure all the necessary resources are provided through their programs.

“None of our systems are easy and a lot of them overlap in what they will or will not provide for a person.”

*-Program Manager of an Epilepsy Foundation affiliate;
parent of a child with epilepsy*

Discussed, also, was the simple fact that, as one respondent pointed out, “No one can please everyone.” A single agency is unlikely to satisfy all—or even most—of the population of people with epilepsy.

“I don’t think in our country having one specific agency or organization is a good solution... Having multiple resources for people really works well because people respond differently to different individuals and to different agencies and organizations, and some people don’t want to be involved with agencies and organizations, period.”

- Nurse Practitioner; Children’s Hospital

Community Connection (12)

More than ten percent of our respondents stressed that the most important aspect of the managing agency or organization of epilepsy self management programs was that it should have strong ties to the community. Some respondents suggested that patient-run programs, supervised by either a service representative or a medical professional, could be highly useful and motivating.

“If we could develop small groups within the community, there may be a lot of value to that. But those groups would have to be coordinated, and that’s quite a large task to many small groups, and they could be patient-run and developed by patients for patients. And that’s quite an exciting concept, but they have to be carefully managed...because people run out of steam. You know, I don’t think when somebody takes on running a small group that they should be stuck with it for the rest of their lives... that’s where local affiliates would be invaluable.”

Others mentioned that many people with epilepsy might be intimidated by larger organizations or complex university health systems. Smaller, community level groups are more user-friendly, as it were, and might appeal to a wider range of people.

Additionally, some thought that a smaller community program, possibly patient-run, might be more flexible in terms of the customization of individual self management programs.

Social Service Agency (9)

Several respondents said that a social service agency would be the best means through which to manage epilepsy self management programs, but added that there is not usually enough funding directed toward that field for it to do so.

“Depends on the nature of the intervention obviously, if this is something that patients can be directed to resources that can be managed easily by a provider and a patient, more specialized or supportive counseling obviously would usually be managed by an outside agency, but if there were funding available, it could be managed through mental health resources or social work resources that exist.”

-Neurologist

Others considered a social service agency to be the best choice because they do not usually have the same fast-paced, high pressure environment that hospitals and clinics can have.

“It does need to be someone that is truly experienced and understands the disorder, not just the medical but the social implications...social workers probably have more time on their hands and I think they could do it, any agency or hospital [does] have health social workers, but they need to be educated to understand the issues.”

-Executive Director of an Epilepsy Foundation affiliate

One respondent pointed out that because epilepsy is often a secondary condition to other syndromes, and that because people with epilepsy have such a high frequency of comorbid issues, it is important for social services to take the lead in self management, so that attention is given to all facets of the issue.

American Epilepsy Society (8)

The respondents who chose the American Epilepsy Society (AES) as the best organization to administer epilepsy self management programs cited AES's already important role in epilepsy education.

“The way it’s kind of broken up now, the Epilepsy Foundation does consumer education and the AES does professional education, and I think you kind of need both. You know, you need to teach professionals how to teach self management...and then it needs to be passed on to the consumer.”

-Clinical Coordinator at a Comprehensive Epilepsy Program of a Children’s Hospital

Others expressed their certainty that the American Epilepsy Society was highly capable to promote self management programs and set guidelines of what would make an epilepsy program acceptable and worthy to be shared with the public.

“I would say there needs to be one agency that’s in charge of working with the plethora of all the, you know, distributing information, doing training...and that certainly to me would be the [AES], that’s the logical place to go.”

-Executive Director of a social service organization for people with disabilities; person with epilepsy

Other (5 and under)

- Epilepsy organizations (5)
- Do not know (4)
- Epilepsy.com (2)
- International League (2)
- Neurology Society (2)
- Employer (1)
- Insurer (1)
- National Association of Epilepsy Centers (1)
- Professional schools (1)
- Refuse to answer (1)

Most Important Outcomes

8. What is the most important **outcome** an epilepsy program can achieve?

Note: to learn how the most frequently mentioned responses to this question differed by respondent profession type (clinician, social service provider, and researcher) and by whether or not the respondents have personal experience with epilepsy, see Appendix B.

Many respondents identified more than one outcome without distinguishing which they considered most important; all outcomes are included in the results below.

Seizure Control (37)

Over a third of respondents cited seizure control as a desired outcome that an epilepsy program could achieve. While many expressed that absolute freedom from seizures is ideal, others discussed that, given the complexities of the disorder, aiming for improvement in seizure frequency and severity is a crucial and attainable goal.

“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.”

- Clinical Nurse Specialist in Epilepsy Program

Some respondents stressed the relationship of seizure control and its effect on other aspects of a patient’s life. One person commented in particular on the incidence of seizures in relation to the risk of other problems.

“More and more research has shown how persistent seizures [are] associated with so many more problems—[they’re] associated with higher rates of unemployment, higher rates of mood disorders, greater risk of SUDEP, you know, sudden death, you know? So the risks associated with poorly controlled seizures are so high, I want to see an outcome be able to impact seizure control...”

-Epilepsy Nurse Specialist; Research Specialist; person with epilepsy

Quality of Life (22)

More than twenty percent of respondents said that an important outcome of an epilepsy program centered on improving quality of life for people with epilepsy. A number of respondents discussed that although absolute seizure freedom is not always a feasible option, coping with seizures and mitigating other stress factors in their lives can significantly improve the quality of life for people with epilepsy.

“Improved quality of life—that’s kind of what it’s 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 it, so that they are okay with having seizures, or they do their best despite having seizures, and that they’re able to manage the other things that impact their quality of life, that would be key.”

-Education Director of an Epilepsy Foundation affiliate

Others discussed quality of life in the context of enhancing enabling factors for people with epilepsy. Specific issues included: navigating the health services system, overcoming the stigmatization associated with epilepsy, and having the skills to manage their epilepsy. One respondent alluded to the relationship between quality of life and factors such as autonomy and socialization.

“The most important outcome would be to help them improve quality of life for the person with epilepsy, and quality of life would mean, the quality of life includes seizure control, it includes such things as employment, it includes socialization, transportation, a number of things...”

*-Information and Referral Coordinator of an Epilepsy Foundation affiliate;
person with epilepsy*

Confidence/Control (20)

The often unpredictable nature of epilepsy can undermine a person’s sense of control over their disorder and their behaviors to manage it. Twenty percent of respondents said that restoring confidence and control to a person with epilepsy is a desired outcome an epilepsy program could achieve. People with epilepsy often find themselves dependent on others in order to manage their seizures and carry out daily activities such as driving. As a result, there can be a drastic shift from an internal to external locus of control which can impact one’s sense of control over his or her life. One significant goal, therefore, is to isolate factors in life that people with epilepsy can control in order to boost their confidence.

“My guess would be that most, that a lot of people with epilepsy would tend to fall more into the external locus of control range because of their belief that...the unpredictability of seizures creates a very limited sense of cause and effect. So there would be a tendency, I think, to contribute their ability to control things more, or to project responsibility for control to more external factors. So if a program could at least measure locus of control, that would probably be good. Particularly in a sense of, you know, for people identifying that they’re able to control more, they have a greater sense of control through self management of things they can manage.”

-Clinical Psychologist; Neuropsychologist

Other respondents were concerned with issues of confidence and control for both managing and living with epilepsy. A recurring response included the notion of a person with epilepsy gaining—or regaining—a sense of empowerment and good self esteem.

One respondent linked self efficacy to the propensity for a person with epilepsy to approach seizures or individual goals in a positive way. Specifically, this respondent implied that if one believes they can control their seizure management, then they will be able to do so. In this sense, a direct relationship between confidence and other outcomes is suggested.

“An epilepsy self management program has to improve a person’s confidence in their ability to do these, so if they don’t believe that they can impact their seizures or believe that they can impact their goals, you know, then none of those will be achieved. So I kind of, self efficacy again is kind of a mediator, but it’s also an outcome.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

Some respondents discussed the foundation that education provides in terms of empowering people with epilepsy and establishing a sense of control.

“I think the education of people, I mean it is really all about the education, so that people can feel in control of managing their epilepsy, and that can only be achieved through education. To me, that is what self management is all about... but people need to be in control of their own chronic destiny.”

-Director of an epilepsy organization in Australia; personal experience with epilepsy

Independence (10)

Independence was identified by ten percent of respondents as an important outcome an epilepsy program can have. Respondents associated autonomy not only with controlling seizures, but also with factors that affect quality of life, specifically in regards to carrying out everyday activities. One person discussed lack of independence and its effect on activities such as driving and working that are often taken for granted by people without debilitating disorders.

“I am not sure it is completely realistic, but that a portion of some of your patients would be independent because of being seizure free. So you would have an increased number of people that were able to be employed, an increased number of people that would be able to drive, and that driving issue is such a big issue in epilepsy because it is a loss of independence... So I think that [the] independence factor is really big in this population of people.”

-Nurse Practitioner

Improved Self Management (10)

Another ten percent of respondents identified effective or improved self management as a desired outcome. Several of these respondents stressed the importance of education and improved understanding in achieving improved self management. Cited examples of topics important to understand in order to perform good self management include what happens during a seizure, seizure types, how medications work and how they need to be taken, lifestyle

changes, how to access information, awareness of seizure precipitants, and how to recognize the onset of a seizure.

“In 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’... so understanding how lifestyle impacts seizures, and understanding why medications work, and how they work, and understanding how timing is important...”

--Educator and Counselor, Epilepsy Foundation affiliate

One respondent described self management in terms of skills that can be applied to any disorder or topic.

“So a self management program, for it to be successful, I think would have its alumni out being expert self managers, which, which means that they are able to manage their epilepsy, monitor, judge, react, evaluate their condition on a continual basis, optimally.”

- Professor, Center for Health Promotion and Prevention Research

A few respondents discussed the importance of comparing post-intervention self management assessments with those that would be conducted prior to the intervention. Because self management skills are quite variable, the key is individual improvement, or in some cases simple maintenance, of self management behaviors from where a participant started.

Other (Less than 10)

- No side effects (9)
- No shame or stigma (7)
- Increased positive affect (6)
- Full potential reached (6)
- Increased understanding and awareness (5)
- Compliance (5)
- Employed or financial stability (5)
- Outcome determined by people with epilepsy (4)
- Increased social connections (4)
- Supportive environment (3)
- Ability to drive (3)
- Normal life as possible (3)
- Medications regularly obtained (3)
- Better coping (2)
- Comorbidities reduced (2)
- Improved public awareness (1)
- Basic needs met (1)

- Having a seizure action plan (1)
- Satisfaction with program (1)
- Understanding benefits of self management (1)
- Realize there are many people with epilepsy (1)
- Using tools for self management (1)
- Life satisfaction (1)

Top Behavioral Objectives

9. What would you say are the top three most important **behavioral objectives** for an epilepsy program to set for participants?

Note: to learn how the most frequently mentioned responses to this question differed by respondent profession type (clinician, social service provider, and researcher) and by whether or not the respondents have personal experience with epilepsy, see Appendix B.

Several respondents had trouble understanding this question, perhaps due the variance in meanings of the term behavioral objectives among different professions. When respondents indicated confusion, interviewers explained that the question sought a list of three things that participants would do differently after an intervention or program that would lead to the desired outcome the respondent previously stated. An example often given was for a weight loss program, behavioral objectives might be exercise daily, record everything eaten, and eat more vegetables.

Compliance Adherence with Meds (59)

Almost sixty percent of respondents listed compliance with or adherence to a medication treatment plan as one of the three most important behavioral objectives. Respondents stressed the need for people with epilepsy (or parents/caregivers) to understand the importance of taking the medication as prescribed, and then to set up a plan or system that facilitates obtaining and taking medications at the right time and at the correct dosages.

“So, one would be medication management. That’s just critical. That they understand it, that they take it, that they keep track of, keep a log of their medications.”

-Program Administrator; public health system

“I want there to be a system in place for medication management. So whether it’s that, for people that have bad memory there’s an alarm that’s set that goes off at a particular time that’s preset, or whether it’s having a pillbox set up...”

-Physician of patients with epilepsy

While the majority of respondents in this response category focused on medication management, some expanded the behavioral objective to include other aspects of disease management such as lifestyle changes to avoid triggers, and knowing when to call their doctor or go to the emergency room.

Healthy Lifestyle and Trigger Reduction (31)

The second most oft-cited behavioral objective concerned healthy lifestyle behaviors that optimize health and reduce potential triggers. The behaviors most frequently identified related to adequate and regular sleep, stress reduction, avoiding alcohol, good nutrition, and regular exercise. These behaviors were identified because they may prevent seizures, contribute to overall health, and help reduce the effects of or help in the management of common comorbidities. Regular exercise, for example, can be an effective stress management technique, can help maintain a healthy weight, and is useful in preventing or reducing depressive symptoms.

“Doing the right thing to minimize your seizures and maximize your health. Don’t drink too much, take your medications, get enough sleep, those sorts of things.”

- Epileptologist; Director of Epilepsy Center

Acceptance, Attitude, and Psychological Coping (24)

The theme of acceptance, attitude, and psychological coping was apparent in answers from about a quarter of the respondents. Acceptance of having epilepsy in particular, and having a chronic condition in general, was seen as a crucial part of healthy coping and effective self management.

Young adults who had been healthy prior to being diagnosed with epilepsy, for example, may be in denial and reluctant to accept the limitations of the disorder.

“Willingness to accept the fact that they do have a disorder, and there is no cure as of now, so they have to work with their physicians, and therapists, anybody, to make it livable rather than just make it gone or cured.”

*-Community Educator and Director of an Epilepsy Foundation affiliate;
person with epilepsy*

Many respondents discussed accentuating the positive: positive psychology, positive self-talk, not letting epilepsy define the individual or rule their lives, rejecting a victim attitude, a focus on personal strength and abilities, and having a positive outlook. These factors contribute to psychologically healthy coping, work against low self-esteem, were linked to resiliency, and can help reduce depression and anxiety. Some respondents discussed the need for people with epilepsy to express, and eliminate when appropriate, their fears, concerns, and anxiety related to their condition in order to help them cope. Other respondents shared stories of people who suffered from the consequences of a negative attitude—they may not live up to their potential because they use epilepsy as a crutch, a reason for staying within a narrow comfort zone.

“Self-esteem, a positive outlook, focusing on what you can do as opposed to what you can’t do, your character strengths, that would be a goal rather than ‘I can’t do this, I can’t do that.’”

-Education Coordinator for an Epilepsy Foundation affiliate

A few respondents focused on the importance of attitude among parents of children with epilepsy and how their attitude can dramatically affect the child. Parents with a child diagnosed with more severe forms of epilepsy often go through a grieving period that includes denial, a state of mind that may impede successful disease management. On the other end of the spectrum, parents may subconsciously lower social and academic expectations of their child with epilepsy. Another potentially harmful, yet common parental response is that of over-protectiveness. These types of responses can impede self management and prevent a child from living up to his or her full potential.

“[Parents] tend to be overprotective, which deprives the kid of social opportunities, of physical exercise opportunities, so that the kid is socially clumsy and physically clumsy, you know, and none of it was meant to be bad, none of it was meant to harm the child, it was all over concern for the child’s safety...”

-Neuropsychologist; Creator and presenter of the S.E.E. program

Understand Epilepsy (17)

Several of the identified behavioral objectives concerned the need for people with epilepsy and/or their caregivers to increase their knowledge about epilepsy: about what it is, what seizures are, the basic forms of treatment and how they work in general. They need to fully understand what they are dealing with and know what to expect. In addition, some respondents discussed a comprehensive education that includes the risks associated with seizures, the importance of safety behaviors to reduce risk, common risk factors and triggers, ways to minimize negative consequences of having epilepsy, and common comorbidities. Such an education would also address the broad spectrum of epilepsy from easily controlled to catastrophic, help people see that they are not alone; and dispel myths perpetuated by ignorance.

Some respondents stressed the individual nature of epilepsy and how patients not only need to have a sound understanding of epilepsy in general, but also that it is critical for them to understand their specific type of seizures and how the disorder manifests itself in them personally.

“Epilepsy is one of those conditions that is very individual to the person, you and I might be diagnosed with the exact same seizure type, but yours looks one way, and mine looks one way, one medicine works for you and doesn’t work for me, and so understanding the individuality of the person’s own seizure disorder, I think would be number one.”

-Educator and Counselor, Epilepsy Foundation affiliate

“That is very individual, but initially what we’re looking for is to increase their knowledge about their condition...because they need to begin to explore that as if it were a study of the most important thing of their life.”

-Neuropsychologist; Director of an Epilepsy Research Program

Recognize Own Triggers (14)

In order to avoid seizure triggers, people with epilepsy or their caretakers must learn the triggers unique to that person. Becoming familiarized with one’s triggers involves education as well as self-observation. One respondent suggested that the person with epilepsy keep a log of exposure to potential triggers and seizure frequency to discuss with their health care provider to assist in trigger identification.

“They should have some insight as to what potential factors in their life might have some impact on the frequency or severity of the epilepsy...”

-Neurologist

“It’s not only understanding what are their triggers, but keeping a log of those triggers and discussing them with their primary care provider.”

-Program Administrator; public health system

Advocate for Oneself (14)

Several respondents identified behavioral objects related to learning to advocate for oneself. Seeking and accessing support services and other resources, talking openly with health care providers, seeking networks of social support, and educating people about their disorder were referenced.

“Be a self advocate for the services they need, for teaching people of the disorder and what to do for them, just being able to communicate with people they live and work with about epilepsy.”

-Behavioral Scientist, government agency

Communication with Health Care Provider (12)

Good communication with the patient’s health care provider was another commonly identified behavioral objective. Respondents stressed the importance of being assertive and proactive in discussions. Patients should ask questions, for example about the potential side effects of newly prescribed medication, or conduct research on their own using the library or the Internet, and then follow-up the research with questions for their physician. Also important to

good communication is the effective tracking, and then reporting, of side effects, triggers, and seizures to the physician.

“I think to ask the questions and try to learn as much as possible, ask their providers the questions. So many times people don’t ask their questions, and then obviously it’s hard for us to know how to help them, so, ask their questions.”

-Nurse practitioner, Neurology

A good relationship, one in which there is mutual trust and respect, is key. One respondent discussed the significance of a patient being honest despite the potential consequence of losing driving privileges. A clinician respondent said it was essential that patients accept the treatment plan—or explain why they won’t, so that the two can then negotiate—and another stressed the need for a patient to understand a provider’s expectations and vice versa, so that they are on the same page.

Accurate Recording of Seizures (12)

Many respondents identified keeping accurate records of seizure activity as a top priority. Whether tracking was referred to as records, journals, or diaries, it was considered essential in helping the physician care for the patient. Some respondents suggested that a person with epilepsy should teach others around them who may witness a seizure to learn how to observe and describe the seizure. Another respondent emphasized adopting a tracking system, whatever it may be, that suited the patient.

“A way for them to keep track of their seizures... I have patients, for instance, who log it on their phone, and some patients who are very, technologically very savvy so they get on the computer and print calendars and keep track of it that way, and some people who just bring in a scrap of paper with stuff written down. But whatever it is, there has to be a system put in place to keep track.”

-Physician of patients with epilepsy

Know and Use Resources (11)

Knowing about and utilizing resources, both in the clinical setting and in the community, are important behavioral objectives key to effective self management. Identified resources included those for obtaining medication and healthcare such as medical assistance programs, how to access epileptologists, transportation and other services that assist with independence, educational or informational resources, employment seeking support, mental health services, available social experiences in the community, advocacy agencies, and Epilepsy Foundation affiliates.

“I would like them to be able to identify and use community resources that can help them cope, that’s huge—do you know what your problem is, do you know where to get help, do you know how to use it, and actually using it...”

*-Program Director for people with epilepsy and mental health services;
person with epilepsy*

Others (10 or less)

- Have a healthy social support network (10)
- Work or otherwise be productive (10)
- Make and keep regular healthcare appointments (9)
- Understand their medications and side effects (9)
- Disclose to others and educate them (8)
- Set achievable goals (8)
- Manage comorbidities (7)
- Increased social skills and socializing (7)
- Be able to problem solve (6)
- Take ownership of disorder (6)
- Emergency planning (5)
- Take action to keep safe (5)
- Feel empowered (4)
- Be active player in health care (3)
- Need to be individualized to each person’s needs (3)
- Use memory strategies (3)
- Obtain or improve seizure control (2)
- Recognize auras (2)
- Be able to access reliable information (1)
- Be aware of other successful people with epilepsy (1)
- Communicate feelings with support network (1)
- Financial management skills (1)
- Be able to self regulate (1)
- Understand realistic education and work goals (1)

Barriers to Participation

10. *What are the common barriers to participation in an epilepsy self management intervention?* 11. *What can be done to reduce these barriers?*

Note: to learn how the most frequently mentioned responses to Question 10 differed by respondent profession type (clinician, social service provider, and researcher) and by whether or not the respondents have personal experience with epilepsy, see Appendix B.

Transportation (53)

The most commonly identified barrier, cited by over half of respondents, was transportation. People with uncontrolled seizures are not permitted by law to drive, and therefore they are dependent on their support networks, special services, and/or public transportation. For those who are fortunate to live in an area with public transportation, it still may not be a viable option due to cost, the fear of having a seizure while in transit, and potential memory problems such as not being able to remember where the bus stop is. For those who can drive or get rides from family and friends, distance required to travel and the cost of gas are considerations as well.

Suggested ways to address transportation barriers:

- Use telemedicine, phone, and the internet
- Locate programs on public transportation lines
- Identify, develop or partner with transportation assistance programs
- Locate programs in the clinical setting

Psychological Barriers (35)

About a third of respondents identified barriers relating to the mental state or attitude of the person with epilepsy. Denial can pose a barrier to participation in self management efforts, either denial of having the disorder at all, or denial that one needs to do anything beyond take the prescribed medication.

“Denial... if you have a big, a grand mal seizure, so the time that you’re in a seizure you’re totally unconscious, you have no idea what’s going on... and you wake up and you don’t know what happened, so you could go on denying that you had problems for a while because it’s not something that you’re actually experiencing...”

-Physician of patients with epilepsy

The comorbid mood disorders such as anxiety and especially depression were frequently linked to barriers or cited as barriers themselves.

“When you have people with mood problems, you end up getting a variety of things that can get in the way of managing it all the way from they’re socially isolated, they have no motivation, to feeling like they can’t do it, you know, their low self confidence, to, you know, a lot of help seeking and rejecting behavior.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

While a few respondents said that some people with epilepsy may feel like they are in control and that assistance with self management is therefore unnecessary, most responses concerned the vulnerability, defeatist attitude, and lack of confidence that can often result from living with uncontrolled seizures. This inability to control seizures can translate to a lack of control in life. Some people may equate self management with full seizure control and thus see themselves as a lost cause, or an inappropriate candidate for a self management program.

“For some people I think it is, they don’t, they have a belief that they can’t make a difference, why should I try, I’m still going to have seizures.”

-Professor of Nursing

This sense of apathy in people with epilepsy can be compounded by low self-esteem and comorbid mood disorders such as depression. People may not believe they are worth the effort it takes to manage well, and they may blame epilepsy or other people for all of their problems instead of taking that responsibility on themselves. People who grew up with epilepsy may have been sheltered and overprotected so much in their youth that they now continue to defer to family members, are not proactive, and don’t believe in their own abilities. Fear of the unknown can also be barrier.

Suggested ways to address psychological barriers:

- Public awareness and education about epilepsy
- Offer or refer to affordable counseling or psychiatric care
- Connect people with epilepsy to others who are successfully self managing; mentoring
- More one-on-one education in the clinical setting
- Hold people with epilepsy or their caretakers accountable
- Encourage more physical activity
- Educate health care providers about comorbidities and referrals
- Be encouraging with people with epilepsy
- Health care providers should approach management with patient as a team effort
- Clinicians need a way to assess patient readiness for self management
- Conduct interventions in schools

Financial Barriers (23)

Nearly a quarter of respondents identified financial matters as a barrier to participation in an epilepsy self management program. Those who explained their answers referred to a lack of resources among people with epilepsy and those who provide services. If there is a charge for a program or service, the cost may be too prohibitive for the person with epilepsy. Many people with the disorder have limited financial resources, and they may also not have access to resources such as a computer, Internet access, or a phone.

“And then money – money is the other big issue. If they’re programs that they have to contribute some funding, most patients feel pretty tight right now.”

-Neurologist

Among service providers, budgetary constraints limit both the number of services available and how many individuals are reached. Some respondents pointed to the lack of reimbursement for support services as a significant barrier.

“We actually have a CPT code for self management right now, but there’s just no money tied for it—no reimbursement tied to it.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

Suggested ways to address financial barriers:

- More national funding for education
- Legislate at state level for guaranteed funding for comprehensive services, as was done in Florida
- Make services reimbursable

Stigma (21)

A commonly identified barrier was stigma. Respondents described how patients they had worked with were unwilling to tell others, or even admit to themselves, that they had epilepsy, whether they were ashamed of having the disorder or a chronic condition in general, feared discrimination or other negative reactions, or were resistant to incorporating epilepsy into their self image. In certain cultures where epilepsy is feared and misunderstood, stigma can be a particularly imposing barrier.

“The stigma business comes in, and this continues unfortunately despite decades now of, of attempt to work with this, still interferes with self management problems.”

-Epileptologist; Director of Comprehensive Epilepsy Program

Stigma can be a barrier particularly in group settings where people feel they are essentially broadcasting that they have epilepsy; one respondent described the many people who were willing to participate in programs via phone where they could retain their anonymity, but not

in person. Another respondent discussed the fear that people with epilepsy have of “getting caught” if they are driving illegally.

Suggested ways to address barriers related to stigma:

- Community education and public awareness raising, including in schools to target youth
- Awareness raising among cultural groups to dispel myths
- Connect people with epilepsy with each other for support and to normalize it; provide social activities
- Have successful people with epilepsy serve as models
- Educate legislators, employers, and professional groups
- Increase visibility of the Epilepsy Foundation of America
- Ensure confidentiality in all programs and services
- Legislate to prevent discrimination
- Mail information to people with epilepsy

Self Management not Valued or Understood (16)

A number of respondents cited as a barrier how many people with epilepsy may not understand what self management is or how it can benefit them. Some discussed how many people are “stuck in the old way of thinking,” where the doctor tells the patient what to do and the patient complies, rather than the patient playing an active role in his or her care. This barrier may be hard to change because many people find it easier to relinquish responsibility and let others make decisions for them than to take on the challenge themselves.

“I think one maybe perception that, from the patient, that the medical doctors and their team are, are intended to take care of the patient, or the person. You know, it’s in the hands of the doctors, you know, they’ll do what’s best...”

-Professor of Neurology

One person pointed to the name, “self management,” as a potential barrier because it implies that the person is on their own in managing their disorder, without the support of family and friends, health care providers, and other resources and services.

“Sometimes it’s the fear that if I do this that nobody, you know, I’m by myself, you know, the doctor’s not going to help me or like, just a misinterpretation of what it [self management] means.”

-Clinical Coordinator at a Comprehensive Epilepsy Program of a Children’s Hospital

Suggested ways to address barriers related to self management not being valued or understood:

- Educate health care providers so they encourage self management
- Make self management part of integrated services

- Train support staff and local community health providers
- Reach patients through the Internet
- Group psychotherapy
- Provide incentives
- Have clinicians see Epilepsy Foundation as a partner in care

Time Conflicts (16)

As with transportation, the practical matter of time and time conflicts was a common response. Time of day, especially for those who work, can be a barrier. Parents of young children have limited time, and parents with a disabled child may find it difficult to carve out enough time to address all of their child's issues. Those in rural areas may need to travel an especially long distance to a program, and those using public transportation may use up a great deal of time depending on bus routes and schedules. In addition to the time required to travel to and attend a program, there may be time demands to commit to the behavioral goals of the program.

Suggested ways to address time conflict barriers:

- Offer multiple options for days and times

Unaware that Program or Help Exists (15)

Several respondents pointed out that frequently, people are not aware that any programs or resources exist. While some lamented the lack of good programs as a substantial barrier, some indicated that good resources do exist, but hospitals and health care providers often do not refer patients to these resources; they may not even know they're an option. A staff member from an Epilepsy Foundation affiliate discussed how they offer resources and educational programs, but they are dependent upon referrals from health care providers to reach people with epilepsy.

Suggested ways to address barrier:

- Public awareness raising
- National marketing campaign
- Community presentations
- Inform health care providers and schools about programs so they can refer
- Encourage word-of-mouth
- Be creative; don't rely on clinical referrals
- Provide organized checklist for clinician to go over self management topics
- Disseminate research findings to clinicians

Lack of Access to Health Care (13)

The difficulty of finding access to health care also poses barriers to self management efforts, as more than ten percent of respondents acknowledged. Barriers included health insurance; the high cost of medications; a lack of epileptologists that may result in long waits for appointments as well as the need to travel long distances to see the specialist; patient dissatisfaction with care; lack of continuity in care and patient-provider relationships; finding a provider who promotes self management; and primary care providers who do not refer to specialists in a timely manner.

Suggested ways to address access to health care barriers:

- Epilepsy learning collaboratives
- Have a single payer system

Programs not Available (11)

Some respondents identified the lack of available programs as a barrier.

“Well you know I’ve never had a patient go through a program, through something as defined as a program. We give them guidelines on how they should manage their medicine and how they should manage their general aspect of staying well. But I’ve never had the luxury of saying well here’s a program, you know, go and participate in this program... they don’t exist.”

-Clinical Nurse Specialist; Clinical Director for Seizure Disorder Center

Suggested ways to address barrier:

- Conduct more vigorous research on comprehensive interventions
- Focus research on sustainable, easy-to-administer, and accessible programs
- Widely disseminate successful programs
- Coordinate programs in each state at a central organization such as a university medical center
- Encourage neurology community to support programs (e.g., Academy of Neurology, Neurology Society, American Epilepsy Foundation)

Cognitive Issues (11)

Respondents identified cognitive issues as a barrier to participating in self management programs. Some people with epilepsy may be cognitively limited in achieving the behavioral goals of a self management intervention due to seizures and/or the side effects of medications. They may have difficulty defining problems to address, may have attention problems, and may not be able to retain information due to difficulties with memory.

“When someone is having multiple seizures, and they’re on medication, their cognitive abilities are affected, so you might tell them one thing about managing their epilepsy, and then tomorrow they are going to forget what you told them, so the retention of information is often difficult.”

-Executive Director of an Epilepsy Foundation affiliate; parent of a child with epilepsy

Suggested ways to address cognitive issues barrier:

- Customize intervention to individual
- Adjust medications
- Improve seizure control

Other (less than 10)

Barrier	Number of respondents	Suggested ways to reduce barrier
Family Dynamics	7	Possible solutions to overcoming this barrier include educating family members and other support people, and providing communication and skills training for people with epilepsy and their families.
Person with Epilepsy’s Lack of Knowledge	5	None specified
Insufficient Time at Doctor’s Office	6	Respondents suggested reimbursing nurses, counselors, or social workers for the work they do with a patient, and reimbursing physicians for any self management work they perform as an incentive to find the time for this aspect of care.
Social Discomfort and Isolation	5	Some respondents advised frequent follow-up phone calls on the part of health care providers to alleviate some of this problem.
Seizure Severity	5	None specified
Patient-Provider Communication	3	Respondents suggested that patient-provider communication be improved by providing a list of topics to providers that will help them guide a patient through a fruitful and thorough discussion. Additionally, group sessions between patients, their families, and their providers with an informative question and answer session would be useful, as would teaching communication skills to both parties on how to effectively deal with one another.

Barrier	Number of respondents	Suggested ways to reduce barrier
Language	2	A couple respondents suggested offering resources, programs, and support groups in multiple languages in order to address the language barrier.
Hard for individuals to identify with a diverse group of other people with epilepsy	2	None specified
Provider's Lack of Knowledge	1	None specified
Childcare	1	None specified

Other suggested ways to reduce barriers that were not linked to a specific barrier:

After respondents discussed barriers, they were then asked what can be done to reduce those barriers. In many instances, respondents did not link their suggestions to specific barriers, and it is conceivable that the following suggestions could address more than one barrier.

- Educate insurance companies
- Focus on the strengths of the person with epilepsy
- Get seizures under control
- Outreach to people with epilepsy and engage
- Partner with employers
- People with epilepsy as peer models or mentors
- Support groups to share experiences
- Reimburse doctors for self management work
- Teach problem solving
- Tie programs to what people already do

Weaknesses and Challenges

12. Of the work that seeks to improve epilepsy self management, is there a weakness or challenge that needs to be addressed? (beyond barriers to participation)

Insufficient Research (22)

The greatest proportion of answers, about twenty percent, focused on the lack of research, concerning both epilepsy in general and more specific research areas in need of attention. One nurse practitioner talked about how she had never seen a useful tool or checklist for clinicians that would help them promote self management with their patients. She and others spoke of the need for more translational research to develop efficient, practical, and useful tools and models for daily practice.

Other specific research areas in need of attention that were mentioned include: epidemiological research concerning differences among races and ethnicities; issues related to epilepsy among women of childbearing age; identification of practical and social problems faced by people with epilepsy; predicting and preventing seizures (e.g., recognizing aura); determinants of self management behavior; mechanisms and impact of seizure triggers such as stress and sleep deprivation; and how people with epilepsy access and manage information.

As one respondent put it, epilepsy self management is “a pretty nascent field... we’ve got a lot of room for growth.”

-Director of Psychiatry and Behavioral Neurology

A number of respondents talked about challenges related to properly assessing self management interventions. In order to provide convincing evidence for funding and support from clinicians, respondents argued, researchers need to measure significant outcomes such as hospitalizations, ER visits, and cost savings. One respondent argued that physicians and insurers would be most convinced of self management’s value if increased seizure control were a consistent outcome, but this is unlikely due to many confounding variables. Another questioned how to best measure a person’s ability to manage. The evaluation designs need to be a robust, controlled study to produce powerful findings; several existing programs either do not measure outcomes at all, or they focus on less significant outcomes such as self efficacy.

“The other challenge is that acceptance of epilepsy, of self management, amongst professionals, amongst payers or insurance companies.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

Some respondents focused on the need for many different interventions for different groups of people, and a challenge was a lack of consensus on which strategies work best for which groups

of people. Recruitment was another challenge to research, especially the challenge of recruiting enough participants when specific criteria such as seizure type and severity are in play. Skepticism and apathy were cited as barriers to participation.

“They’re not sure of what’s really going to happen and how they’re going to be helped and they tend not to want to participate unless everything is really lined up so they can see how it’s going to benefit them.”

-Executive Director of an Epilepsy Foundation affiliate

Narrow Approach to Addressing Epilepsy (18)

The second most common group of answers relates to the challenge of providers’ limited, narrow approaches to addressing epilepsy. Such approaches focus on seizure control and do not integrate care for mental health comorbidities or the education and services that support self management. Health care providers often do not identify, diagnose, or treat the mental illnesses common among people with epilepsy; comorbidities such as depression may not be taken into consideration when patients are expected to take on certain responsibilities for their care. The lack of communication between neurologists and those who provide psychosocial services was cited by one respondent.

“So, your neurologist is focused on seizure control, your psychosocial people are focused on the, you know, these other aspects. In some cases they’re talking with each other, but in some cases they’re not. Communication is a very important aspect.”

-Pediatric Neuropsychologist

Some respondents simply stated that there isn’t enough self management taking place, whereas others discussed how many physicians are unclear on the concept of self management. Specialists in particular have been trained to focus on seizure control through medications, neglecting to take into consideration other methods of treatment or needs of the patient.

The concept of self management can also be unclear among patients and families. More need to understand and embrace it, but this understanding, as some respondents argued, needs to come through education from health care providers with good knowledge of services and resources that support self management. The dichotomy between psychosocial and biological research that one respondent cited may contribute to the barriers to an integrated approach. It was suggested that people with epilepsy would benefit from a switch from the medical model to the recovery model for epilepsy.

“The recovery model, which is used in the mental health system, is a way of reframing the chronic illness of depression in mental health. If we use the recovery model in epilepsy, suddenly the stigma would be less, the hopelessness and the despair would be

less, people would say I have this condition, but I know how I can get better, and this is how I define it... it is really empowering, and really hopeful.”

*-Program Director for people with epilepsy and mental health services;
person with epilepsy*

Another related challenge is garnering support for psychosocial interventions from health insurance companies, government agencies, and the agencies administering the self management program.

Lack of Awareness, Stigma (14)

Lack of public awareness and stigma were identified by many as challenges in the work to improve epilepsy self management. Respondents discussed the inter-related challenges of stigma, public misunderstanding, negative attitudes towards and discrimination against people with epilepsy, and disclosure and social interaction challenges. Some people with epilepsy can miss self management opportunities because they don't feel comfortable talking about their disorder. A diagnosis of epilepsy can be quite scary for some, in part due to public misconceptions and stigma.

By helping a community better understand epilepsy and how it affects people, acceptance on the part of the community, as well as the person with epilepsy, can be promoted. Respondents also identified school personnel, police officers, and professionals who work with people with epilepsy in need of more education. One person discussed the public misperception that all seizures are of one type.

“Most people still think epilepsy is a tonic-clonic seizure is where you drop to the ground and you are jerking, and there's actually thirty different types of seizures, so that is why I am so passionate about the education.”

*-Epilepsy Services Specialist for an Epilepsy Foundation affiliate;
person with epilepsy*

People with epilepsy from certain ethnic groups such as Indian, Hispanic, and Hmong may suffer disproportionately due to cultural beliefs about epilepsy. In some cultures people with epilepsy may not be accepted by their family.

“It is something that is hidden away, it is not discussed, it is a bad thing..”

-Social Worker for an Epilepsy Foundation affiliate

Two respondents spoke of how epilepsy lags behind other disorders, such as autism and breast cancer, in terms of public awareness and support, perhaps in part due to misconceptions and stigma. They discussed the difficulty in engaging people in the movement and cited the dearth of well known events for epilepsy like telethons or walks such as breast cancer's Komen Race for the Cure.

One respondent discussed stigma, but in the very different context of how the epilepsy movement's long-standing efforts to reduce stigma may actually impede self management efforts by downplaying the many difficulties people with epilepsy can face.

“The epilepsy movement, forever—for years and years—have tried to emphasize that people with epilepsy are just like everyone else... I don't think they are going to ever come out and try and present it like that, I don't know how you are going to get around that, I don't think they are going to come out and present anything on the negative.”

*-Information and Referral Coordinator for an Epilepsy affiliate;
person with epilepsy*

Programs Not Accessible (13)

The lack of accessible programs was of concern to some respondents. A handful of people discussed the inadequacy of resources in the general community, whereas others considered specific concerns. One person explained how those who most need help with self management are least likely to be able to attend multiple in-person sessions, and another suggested that distance delivery methods need more attention. Distance delivery was, however, a concern of a respondent who thought that web-based program formats leave out a whole group of people. Not reaching enough people with epilepsy, people having to wait for services when they need it most, and the scarcity of support groups and other resources were also cited challenges.

“It may be a fantastic program but if you can't get people there, you can't take advantage of it.”

-Executive Director of an Epilepsy Foundation affiliate; person with epilepsy

When people are unaware that services even exist in their area, accessibility is obviously limited.

“I cover twelve counties and I have three support groups and I'm always having, I always have people calling me who said they hadn't ever heard about the support groups or even about the Epilepsy Foundation.”

-Epilepsy Affiliate Services Coordinator; has a family member with epilepsy

Lack of Funding (10)

About ten percent of respondents said that lack of funding was the biggest challenge that needed to be addressed in terms of epilepsy research. Respondents discussed how supportive services such as social work, psychotherapy, and support groups are not funded or covered by insurance. Others told stories of how, in the current economic climate, even the few public services that are currently available are now on the chopping block. Inadequate public awareness and advocacy work relates to deficient funding levels for research and services.

“If you’re not the disease of the week or you don’t have a lot of people or a lot of organizations in your corner or exposure, you’re not going to get the funding.”

-Clinical Social Worker in Neurology

Healthcare System and Insurance (10)

Several of the weaknesses and challenges cited correlate with problems in the U.S. healthcare system, which one respondent described as “broken.” Insurance issues and ability to pay for costly medical services, medications and other treatments were a top concern. Also cited were problems with follow-up care, regional shortages of neurologists, deficiencies in communication between specialist and primary care provider, navigating the healthcare system, and long stretches of time between appointments. Two respondents questioned how self management, given the time it consumes and the fact that it cannot be reimbursed, can fit into clinical services in the current healthcare system.

“We have really no access to social workers, psychologists, counselors, who patients have to find on their own and pay for, because most of the time insurance won’t pay for it.”

- Clinical Nurse Specialist in Epilepsy Program

Individualizing Interventions (7)

Clearly, epilepsy is not a one-size-fits-all type of disorder; for example, there is a wide spectrum in terms of seizure type, severity, syndromes associated with epilepsy, comorbidities, and cognitive impairments. Each population has its own set of barriers, needs and limitations, and a challenge identified by several respondents was how to individualize care plans and other interventions to optimize management. Researchers need to develop and assess more individualized interventions.

“You need to study people with same seizure types, same syndrome, you know, different severities, and so you can’t just group and say I’m going to look at a hundred people with epilepsy and give them the same program.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

One respondent was most concerned with how we can best help the most severely challenged people with epilepsy. Another discussed the need to be sensitive to developmental differences in children and teens of varying age. A researcher said too much work has centered on changing specific health behaviors and pointed to the need to instead focus more on teaching problem solving skills, to enable people to address their individual problems.

“Allow people to come up with their own, you know, their own idea of what’s important for them... we tend to just talk about how do we make sure patients know to take their

pills... but there's, there's not that much of, 'what is the problem you're experiencing?'"
-Nurse

Addressing Cognitive Issues (5)

Cognitive impairments present an obvious challenge to self management efforts, and some respondents said that not enough attention is being paid to this challenge. Some speculated that the challenge has been skirted and other, less complicated interventions have been pushed. Interventions need to target varying levels of cognitive ability.

"I think certainly expanding the concept and belief of self management to people with knowledge and intellectual disabilities is very important, and that's a definite gap."

*-Executive Director of a social service organization
for people with disabilities; person with epilepsy*

Other (less than 5)

- Insufficient dissemination (3)
- Difficult for people with epilepsy to obtain disability benefits (3)
- Lack of empowerment (2)
- Lack of awareness of sudden death in epilepsy (2)
- Territoriality for funding (2)
- Health education content too simplified for a complex disorder (1)
- Discrimination (1)
- Latino/Hispanic population not well served (1)
- Challenge of changing behavior (1)
- Insufficient cultural competency (1)
- Enabling by family and friends promotes sense of helplessness (1)
- Many challenges faced by families interfere with self management (1)
- Medication side effects interfere with self management (1)
- Entitlement personalities of some people with epilepsy (1)
- Reliance on seizure reporting from patient is weakness in clinical setting/research (1)
- Inadequate representation of people with epilepsy on boards (1)
- Need to focus on fear of death and brain damage, not stigma (1)

Most Effective Strategies

13. I'll read several pairs of different strategies that may be employed in promoting epilepsy self-management. For each pair, please tell me which one of the two you think is **more effective** in improving self-management of epilepsy. For some of these pairs, it may seem difficult to choose one over the other, so feel free to comment on why choosing one is difficult.

Family or Individual: which is more effective? (n=98)

Family	65%
Both	14%
Individual	11%
Depends	10%

The majority of respondents, 65%, preferred an intervention that included the family. None of the 11% of respondents who selected individual gave any reasons for their choice.

Respondents' reasons for selecting *family*:

- The more support a person with epilepsy has, the better; it is important and usually beneficial to have family on the same page
- Epilepsy affects the entire family, and even if the person with epilepsy will not go to a self management program, a family member can attend, learn the material, and then work with the individual at home
- It is often useful to approach epilepsy as a manageable community and family challenge; a 'we're all in this together' approach
- The family needs to be supportive of whatever an individual in the household is doing; interventions can provide families with understanding
- Treat the individual in the context of a system
- Kids with epilepsy must have their caretakers/family involved

Some who selected *family* had some concerns and stipulations concerning their choice:

- It is optimal to include the family, but many people with epilepsy don't have family involved; it is ideal if family members are receptive and willing to go
- Involving family is fraught with issues and including them really needs to be subject to a patient's inclination.

- There should be some kind of a separate component for family and individual. Family needs to be involved, but a person with epilepsy has to work on self management skills on an individual basis as well.

Those who said both *individual* and *family* recognized the importance of developing self management skills on one’s own, as well as the great benefit of a supportive family with a more encompassing knowledge base. Some suggested that interventions should start with the individual and then move to the family, while one respondent suggested an intervention that has modules for just the people with epilepsy, just the family, and ones where all are together, depending on the goals of the modules. For example, people with epilepsy may benefit from a support group without family where they can share their unique problems, or an overprotective mother who is impeding her child’s self management efforts may benefit from an intervention targeted specifically to worried parents. Both types of interventions need to be available; epilepsy is not a one-size-fits-all disorder, and neither are the individuals nor families who are affected by it.

Respondents who said that whether an intervention targets the family or the individual depends on several different factors cited age and independence level of the individual; cognitive abilities; timing; comfort level of the individual; and dynamics within the family.

“You have to assess that individual in their family system. I think sometimes families can be detrimental to a learning process, and, and timing would be an issue in that... in some situations, the family would be absolutely ready and embracing and ready to go, and in others it wouldn’t be that way.”

-Clinical Nurse Specialist

Clinical setting or community setting: which is more effective? (n=101)

Community Setting	43%
Clinical Setting	41%
Other response	16%

Respondents were essentially evenly divided in their choice of settings. Some expressed how difficult it was to choose one setting because it depended so much on the individual person with epilepsy and other factors such as the facilitator and geographic location.

Reasons people voiced for selecting *community setting*:

- People can be inhibited in a doctor’s office, while there is less fear and loss of control in a community setting
- People will be comfortable, will feel freer, and will be able to take in more information
- With a community setting, an intervention can be tied to something people are already doing, like attending church or getting a haircut

- Self management ultimately occurs in the home and community where a person with epilepsy resides, so learning self management should occur there as well where specific strategies can be developed
- Reach can be broadened through community organizations
- Community settings are more practical, even if they're not as effective; there is too much chaos and too many time constraints in the clinical setting

Some respondents chose community with the caveat that a health care provider be involved, because validation from the clinical setting is powerful.

Reasons people voiced for selecting *clinical setting*:

- Almost everyone visits the doctor at some point, but not everyone will seek out community programs
- The clinical setting is where a patient first receives diagnosis; it can be the base for initial self management exposure and can work in partnership with community interventions
- People are more willing to listen to doctors and take their advice because of their credibility and expertise
- Epilepsy centers are high functioning places devoted to epilepsy and employing professionals with expertise, subspecialties, and multidisciplinary approaches
- People are more receptive in a clinical setting in terms of timing
- There may be trust issues in the community if patients don't know the people involved in the intervention
- Many people would prefer one-on-one in a clinical setting versus the group format of an intervention in the community

Those who did not choose a setting indicated that the setting depended upon other factors like the type of community and the person, or said that the setting did not matter, or indicated that both settings were equally good. Several people discussed the importance of both settings interfacing in a partnership where patients benefit from the expertise of the clinicians and then have long-term support in the community where they live. In the clinical settings, patients would receive information one-on-one from professionals and then could move to the community setting and network with others who share similar experiences. Respondents argued that the two settings can reinforce each other, and either setting would be less effective than a combination of the two.

“Both, with clinical setting first and community setting second... if you don't have, you know, your clinical team on the same page as you, you're not going to go any further... but what makes it really work is when it can fit into the patient's community... have programs that are out there where the patient is and whether that's the Internet, or whether it's available in a community setting where they can go to some place and do it, I mean that's where the patient's really at.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

Telephone or Face-to-face: which is more effective? (n=99)

Face-to-face	84%
Telephone	9%
Depends	7%

The majority of respondents selected face-to-face, whereas only 9% selected telephone. Many of those who selected face-to-face, however, recognized that while face-to-face may be ideal, it is often impractical, especially given the transportation barriers faced by many people with epilepsy. Respondents argued that face-to-face is most effective because a relationship and rapport can best be better established through personal contact, where both parties can communicate with non-verbal cues in addition to speaking, an objective that is particularly important for a complicated disorder like epilepsy.

“It’s important to have a rapport with the patient in that initial coming to terms with the disorder, and, and moving them from somebody who’s confused, concerned, moving them to a process of acceptance, skill raising, and management expertise, I think that, that that involves a relationship, it’s not simply an information transition... initially face to face consultation is optimal.”

-Professor, Center for Health Promotion and Prevention Research

Face-to-face contact also helps with the educational process; the educator can better understand the situation of the individual, and better determine whether participants have the will or readiness to learn, and whether they understand the information. Additionally, face-to-face may allow for more types of educational activities and interactions, including the development of social connections among group participants in a way that cannot be realized over the phone.

Some who selected face-to-face conceded that a phone intervention could be very similar, mainly if a relationship has already been established; telephone interventions could be especially useful for follow-up and encouragement. Those who selected telephone as the primary means of communication argued that the telephone allowed for greater access, as most people have either a landline or a cellular, it requires less time, and people can be reached more frequently. One respondent thought many people would feel more comfortable with the relative anonymity of the phone. The respondents who said their answer depended on the circumstances cited factors such as location, comfort level of participants, and cognitive level of participants.

Web-based or Phone-based: which is more effective? (n=94)

Phone-based	46%
Web-based	31%
Depends	20%
Both	3%

Nearly half of respondents chose a phone-based intervention as opposed to the 31% who chose web-based. The top reason respondents chose phone-based was the issue of access. Not everyone has access to the Internet, so phone-based interventions can reach a broader scope of the population. Respondents also thought that some people would prefer the more personal human interaction afforded by phone and added that it can be hard to assess cognitive levels and emotional states over the Internet. Conversations can be tailored over the phone, and patients can be kept on track and on task, whereas some people would have problems following and paying attention to online material.

The reasons people chose a web-based format were diverse. Some respondents referred to research evidence supporting its effectiveness. Others discussed the advantages of a medium that allows for the use of multi-media including photographs, graphics, audio, video clips, text, quizzes, the potential for real time communication, and even eye-contact via web cameras. Users can access more information online, and the learning can be more user-controlled. Some people may prefer to communicate using the written word. Unlike most phone-based interventions, asynchronous uses of web-based interventions allow users to participate at their leisure. One respondent selected web-based only if it were facilitated, and another discussed the value of an online intervention for clinicians that would help them provide information to patients and refer them to appropriate resources.

Some of those interviewed said their answers were dependent on the desired outcomes of the intervention as well as the target population's access to the Internet, their age and comfort level with technology, and their communication and learning preferences. A few respondents said that both formats should be offered to address access issues.

Print or Electronic Materials: which is more effective? (n=98)

Printed	45%
Electronic	22%
Depends	25%
Other	8%

Many respondents indicated that, again, access is an important consideration in selecting an intervention format, as not everyone has access to a computer or is comfortable with electronic technology. Many of the reasons respondents gave for their choices, in fact, echoed what was said about web-based versus phone-based format. Some pointed out, however, that electronic

materials can be designed to also be printed out so that people without computer access or those who prefer printed copies will be accommodated. Also, electronic materials can be much easier to produce and widely distribute.

A few respondents thought both should be offered, and others said they did not see a real difference between the two formats.

Group or One-on-One: which is more effective? (n=94)

Group	44%
One-on-one	37%
Depends	14%
Other	5%

The reasons voiced for choosing the group format, by and large, had to do with the value of people who are dealing with similar issues coming together and benefiting and learning from one another's experiences. Participants can share their feelings, opinions, ideas, and strategies, and feel more comfortable opening up to a group of people who understands what they're going through. Group sharing can help normalize feelings and provide emotional support.

“Large groups have some therapeutic advantages that don't exist in any other form of therapy... it's especially good for issues about guilt and stigma... And of course, what are a couple of the biggest problems in epilepsy? If you're a parent, it's guilt, and if you're anybody that's got epilepsy or related to a person with epilepsy, it's stigma.”

-Neuropsychologist; creator and presenter of the S.E.E. program

Most of the respondents who chose one-on-one recognized the value of group sessions as well, and many suggested that both had their place, particularly an initial one-on-one format followed by group sessions. Reasons for choosing the one-on-one format included being able to recognize and address cognitive issues that would get lost in group settings and the time and ability to delve deeply into an individual's unique circumstances. One respondent argued that a group format does not work because one or two participants can dominate the conversations.

Format choice can depend on a number of variables including issues addressed, goals of the intervention, setting, privacy issues, skill level of the facilitator, preference of the participant, and cognitive level of the participant. Some people do well with the dynamics of and connections made in groups, whereas others are not comfortable in a group setting and prefer one-on-one. Certain issues, such as strategies to reduce stress, may be well suited for group format, whereas other issues, such as examining deep psychological barriers, may require one-on-one work. With the one-on-one format, the facilitator can better understand the individual's history and thus tailor the intervention. However, as some respondents pointed out, limited resources may call for group format.

Weekly or Retreat: which is more effective? (n=94)

Weekly	63%
Retreat	22%
Depends	5%
Other	10%

Almost two thirds of respondents chose weekly sessions whereas 22% chose a retreat format. Allowing people to learn gradually over time, reinforcing the material by repeating it on a regular basis, and keeping it fresh in people’s minds week to week were the most common reasons cited for choosing weekly sessions as the preferred intervention format. Given that many people with epilepsy experience problems with memory, regular repetition is particularly important. Repeated intervals also provide time for rehearsal of behavior change and feedback. Weekly sessions can be easily incorporated into a person’s schedule as a routine event, whereas it can be hard for people to commit to an entire weekend or more for a retreat. The idea of a retreat can also be scary for some people. A few respondents suggested that although regular sessions are preferable to a one-time retreat, monthly meetings may be a better time interval.

Those who chose the retreat format said that the intensity of a retreat is more effective; transportation barriers are reduced with a one-time event; retreats can be fun opportunity for socializing; retreats are more practical; and a weekly intervention might be weakened by drop-outs over time.

Among a handful of respondents, the choice depended on different considerations. One consideration is age and developmental stage of a child; a respondent thought retreats were the best option for families. Another respondent discussed how where a person is on the continuum of treatment can help determine the most appropriate format because, she argued, weekly sessions may be too much for someone who is newly diagnosed. Other key considerations are the availability of good public transportation in the area and the specific goals of the intervention.

“Employment strategies, interviewing techniques—that might be great in a retreat... [but] self management is a process, it’s a process over time, so where is the follow-through, where is the ability to go back and check where the patient’s at, where, have their priorities changed, how can you build on their next step—you can’t do that in a retreat.”

-Epilepsy Nurse Specialist, Research Specialist; person with epilepsy

A small group of respondents suggested that both formats be employed so that an intense retreat is followed by regular follow-up sessions. One respondent argued that neither is realistic given available resources.

Self Administered or Facilitated: which is more effective? (n=98)

Facilitated	80%
Self Administered	5%
Other	15%

The vast majority of respondents selected facilitated over self administered. Some saw a place for both and thought that both should be offered, but respondents clearly felt that facilitated interventions would lead to greater success with more people. Those who chose self administered did not voice a reason, but several respondents suggested that facilitated be followed by self administered, and one tied a self administered format to the goals of self management.

“If you want it to be true self management then it’s self administered... that’s the whole purpose of it, in the end.”

-Staff, Epilepsy Foundation of America

Respondents’ reasons for selecting *facilitated*:

- For most patients, self management is very difficult to do on their own
- Important for intervention to be facilitated by both a peer and someone with medical knowledge
- Participant can get distracted if all the self management is self administered; a facilitator can help keep things on track
- Facilitator can back off when needed, whereas in self administration, a participant might not make headway
- If self administered, confrontation of reality can be omitted or overlooked by the person
- At the outset, facilitated is best, followed by self administered

Most of the 15% of respondents who fell in the *other* category either said that both were needed, or that the response depended on the individual’s capabilities, goals and stage in the process.

“Depends upon what the patient goals are. There’s an element to self administered that I think is very important because it depends upon the patients, you know, their motivation, so that they’re going to do it if they’re truly motivated. However... you see that role of facilitation’s pretty critical that you can help correct misinformation, you can help them better understand their priorities of what information will help them match their priorities or not. So if I was to be pushed, facilitated vs. self administered, I think would say facilitated would come out number one with a role of self administered for specific areas.”

-Epilepsy Nurse Specialist; Research Specialist; person with epilepsy

It was thought that a subset of people with epilepsy would do well with a self administered technique, but facilitated was recommended for people with cognitive difficulties, the elderly, and those from low income populations. Individual preference, motivation levels, and learning styles were also important.

“This should be a patient choice in terms of whether they want to, you know, have somebody lead through it or some patients and people are motivated enough and inspired that they want to make changes and go through a self-paced module or book or workbook themselves.”

-Professor, Health Behavior and Health Education

Which is more effective?

Education or Case Management (n=96)	
Education	56%
Case Management	31%
Other	13%
Counseling or Education (n=96)	
Education	55%
Counseling	17%
Both	16%
Other	12%
Case Management or Counseling (n=96)	
Case Management	52%
Counseling	30%
Other	18%

From people’s responses to these three, interrelated questions, it was clear that there are many interpretations of the terms “case management” and “counseling.” When asked, interviewers explained case management as coordinating care and connecting people with resources, whereas counseling was more of a psychotherapy approach. Only a small proportion of respondents, however, asked for clarification.

The responses to the three questions in the tables above indicate that education is considered the most effective approach, followed by case management and then counseling.

Education or Case Management: which is more effective? (n=96)

Education	56%
Case Management	31%
Other	13%

Respondents' reasons for selecting *education* over *case management*:

- Broad perspective that could cover and organize a lot of different topics and aspects of self management
- Leads to effective case management
- Implies hands-on
- Some thought that education is ultimately the answer to a lot of the issues raised throughout the survey
- Parents are the best case managers, necessitating education for parents

Respondents' reasons for selecting *case management* over *education*:

- Patients need the most help with case management
- Education is part of case management
- Case management is a 'bigger picture' approach
- Case management is tailored to the individual and highly individualized, whereas education is more of a mass sharing of information
- Case management engages the participant more in the process
- If case management includes coordinating care with all professionals involved in a particular case, then case management is preferable than education

Among the responses falling in the *other* category, answers indicated both education and case management were needed, it depended on the person, or that the two were the same thing. One respondent suggested that education be followed by case management for optimal success. Another respondent argued that the choice depended on what case management entailed.

"A case manager, if they're just trying to refer them to different groups and not helping them understand why they might need these, well no wonder we have people with misinformation and not able to manage their health. People are just trying to tell them what to do. You don't need more people telling them what to do. You need people to listen to them and find out what their goals are, what their problems are, and now let's help them understand the appropriate information, teach them the skills that they need, find the resources in their area that will help them."

-Epilepsy Nurse Specialist; Research Specialist; person with epilepsy

Counseling or Education: which is more effective? (n=96)

Education	55%
Counseling	17%
Both	16%
Other	12%

Respondents' reasons for selecting *education* over *counseling*:

- Education is a broader perspective
- Education can include, or function as, counseling, but counseling cannot easily incorporate education
- Counseling is not effective
- Counseling has a place for some people, but education is a global strategy that reaches more people and hopefully helps people with epilepsy understand their situations better
- Self management is more about training, not counseling for mood or emotional issues; however, it was acknowledged that counseling is important in the morbidly depressed

"I don't think we should think of self management training as a counseling exercise, I think we should think of it as a training, as an educational exercise... that skills training could be negatively impacted by issues that are cognitive, like my lack of knowledge or my lack of confidence, or the feeling that, you know, this isn't going to work, but those can be overcome with the training, with the management training. However, if I have a depressive state that has me sitting in a corner, immobile, then I need, I need adjunct counseling to get me into the cognitive state where I am receptive to the self management program training."

-Professor, Center for Health Promotion and Prevention Research

Respondent's reasons for selecting *counseling* over *education*:

- Counseling involves skill building
- Counseling could encompass a broader approach and might include some things that education could miss.
- Counseling can include education

Again, among the responses falling in the *other* category, answers indicated both education and counseling were needed, or that the two overlap or intertwine considerably, it depended on the person, either was effective, or that the difference between the two was unclear.

"I'd like to say both. I mean I think a good counselor does a lot of education and a good educator does a lot of counseling."

-Physician Assistant in Neurology

The choice of counseling over education will depend on the person’s age, culture, and where they are at in terms of acceptance and coping with the disorder. One respondent, for example, discussed how angry many people are towards their health care providers after trying medications and experiencing significant side effects, and counseling may be needed to work through the anger.

“I do more educating than counseling, but I do both. And when the counseling is needed, it is an inhibitor to wellness if you don’t get it. And it has to be timely and efficient, in other words it can’t drag out like we do in psychotherapy. It has to be knowledgeable counseling that is to the point in the given situation.”

-Neuropsychologist; Director of an Epilepsy Research Program

Case Management or Counseling: which is more effective? (n=96)

Case Management	52%
Counseling	30%
Other	18%

Respondents’ reasons for selecting *case management* over *counseling*:

- Case management is broader in scope and longer term; counseling can fit within its scope
- Case management includes the whole plan of care, including psychosocial aspects
- If there are no psychological comorbidities, skills training is most important
- It is important to keep track of all the players and their communication with each other
- Coordination of care and services are more potentially useful than counseling
- Counseling is not effective

Respondents’ reasons for selecting *counseling* over *case management*:

- Case management is too resource intensive; it helps to keep people out of the hospital, but does not work otherwise
- Counseling is better for promoting self management
- Self management cannot be done without behavioral counseling

Some respondents saw no difference between counseling and case management, and one said that it didn’t matter as long as the patient worked on cognitive-behavioral therapy strategies. Many respondents thought that both were needed, or that education was required in addition to these two strategies. The choice between counseling and case management, some argued, depended upon the individual’s circumstances; for example, someone with developmental disabilities as well as epilepsy may be in need of case management, whereas others may only need counseling.

Nurse Specialist or Social Worker: which is more effective? (n=96)

Nurse specialist	47%
Social worker	18%
Either	18%
Other	17%

Nearly half of respondents selected nurse specialist, whereas only 18% selected social worker. Another 18% of respondents, however, indicated that either could be effective, and several of the respondents who selected nurses voiced hesitation because they said it depended on the background of the individual.

Respondents' reasons for selecting *nurse specialist*:

- Nurse specialists have a strong medical background
- Nurse specialists have a broad perspective
- Nurse specialists can serve as a bridge between neurologists and social workers because they have a degree of understanding of both the biomedical and psychosocial aspects of epilepsy; this can be a critical role because both aspects are so intertwined in epilepsy
- Nurse specialists are the more practical choice because so few social workers specialize in epilepsy
- Nurse specialists generally have good communication skills
- Nurse specialists tend to be confident, an important attribute for self management

None of the respondents who chose social workers voiced a reason for doing so, but those who said that either professional could be effective voiced their reasons:

- The type of professional is not as important as the professional's training and ability to take their patients seriously and put demand on them
- Either would be effective as long as they are trained in case management, counseling, or education
- While nurse practitioners have more medical background, social workers have a deeper understanding of psychosocial aspects and a number of helpful skills
- Knowledge, experience, and personality are more important factors than profession
- Depends on the setting of the intervention
- Depends on the skill set of the facilitator; are they well-versed in the topic, and have they taken care of people with epilepsy?
- The value of multi disciplinary work is no better illustrated than in the world of epilepsy; there aren't enough resources to say both, so either would be fine.

Several responses, grouped in the "other" category, refused to select an answer based on reasons like the ones listed above. A handful of the "other" responses argued that a team consisting of both professions was ideal.

“They both bring different things to the table that allows for a really nice mix. The social workers are trained to deal with certain issues that patients have to struggle with and wrestle with, and nurses are trained to deal with certain issues, and... I don’t know that one is any better than the other, they just deal with different problems.”

-Epileptologist; Director of Comprehensive Epilepsy Program

Among the answers that fell within the “other” category, three indicated that neither profession is appropriate. Clinical neuropsychologists and rehabilitation counselors were suggested instead, and one respondent argued that nurse specialists are too busy addressing patients’ clinical needs, there are not enough social workers trained in epilepsy, and the rest of the social workers are bogged down with paperwork and referrals.

Health Educator or Physician: which is more effective? (n=97)

Health Educator	64%
Physician	26%
Other response	10%

The majority of respondents selected health educators over physicians. Many respondents argued that physicians simply do not have enough time, whereas others argued that health educators are specifically trained to educate and will thus do a better job in the area of teaching self management. Physicians are trained to diagnose and treat disease, and the system they work in is set up to support and reward that limited scope through reimbursement and rating scales. Some respondents cited a communication gap between patients and physicians, and one even talked about how physicians are not welcome at patient support groups because participants often complain about their physicians at the groups.

Despite these reasons for selecting a health educator over physicians, respondents recognized the credence many patients place on what the doctor tells them. They suggested that physicians can have a critical role by “throwing weight behind a self management plan.” Their presence can reinforce the goals of an intervention and should be incorporated whenever possible. One respondent suggested that self management be initiated, encouraged, and continuously reinforced by physicians in concert with an intervention led by a health educator or other professional.

Lay-led or Professional-led: which is more effective? (n=99)

Professional-led	66%
Lay-led	14%
Both	11%
Other response	9%

Professional-led interventions were the choice of two thirds of respondents, but 20% of those interviewed indicated that a team comprised of both a professional and lay person would be ideal, or that either could work depending on the circumstance. Those who commented on why they chose professional-led interventions cited the importance of having medical issues addressed appropriately. Program participants typically want to know if they were prescribed the correct medications, and professionals need to address such questions. A respondent thought solid knowledge of self management is more likely among professionals, and another argued that participant turn-out is much higher when a professional such as a physician is part of a program.

Those who explained their choice of lay-led interventions cited the value of having a facilitator or leader who has personal experience with epilepsy. One respondent argued that studies have shown that having either a professional or a lay person lead the intervention can lead to behavior change, but utilizing lay leaders is less expensive. Another cited that lay leaders can be less threatening to participants. Some respondents agreed that a lay person could be a good choice, but emphasized that they would need to be well trained in the program content and experienced in group facilitation.

Several respondents argued that using both types of leaders is ideal. Some favored a team approach wherein the credibility and expertise of the professional is complemented by the power of hearing from someone who has personal, real life experience with managing epilepsy. Others thought an intervention should be first led by professionals and then later transitioned to a lay-led format, primarily due to limited resources. One respondent with positive experiences in online, peer-led support groups that are overseen by a professional who is occasionally involved in discussions, argued that lay-led interventions have great value for both the peer leader and the participants, who can benefit from experiencing the peer leader's control and self confidence.

“The benefit of that is that the person with epilepsy is in control and that’s a very, very critical concept of epilepsy self management, that they’re central to this, they’re not on the outside, they’re central to it, and if you can help them not just by being the one who has to do stuff but they actually grow into a role of also facilitating and promoting and leading, you have just increased their self-efficacy and confidence and ability to manage epilepsy a thousand-fold.”

-Epilepsy Nurse Specialist; Research Specialist; person with epilepsy

Some respondents did not choose either option because they said it depended on the personality and training level of the leader, and on the specific issues being addressed.

More Strategy Recommendations

14. *Is there anything else you'd like to recommend about intervention strategies?*

CONSIDER: recruitment, setting, format, methods, staffing, theoretical frameworks

No more to say on strategies (20)

Twenty percent of respondents had nothing more to add about intervention strategies addressed in the previous question.

Recruitment (14)

Nearly fifteen percent of respondents cited recruitment as an important issue when thinking about details of an intervention strategy. Recruitment can be a challenge, as evidenced by the many reasons given when respondents were asked about barriers to participation. Connecting people to existing resources, let alone a new program, can prove arduous. Several respondents advised working with health care providers in the clinical setting.

"I review the clinic schedules in advance the week before and screen who we can recruit, and we have someone in the clinic, we sent out letters to our family, they know they are going to be approached, and our research assistant who approaches the family and explains the study while they are in the clinic visit, which you know, has been much more fruitful, than the other ways we have tried to do it..."

-Pediatric Nurse Practitioner

Other respondents stressed the importance of convincing potential participants of the value of the program and how it can meet their needs. Making sure a program can meet participants' needs involves careful local research of the target audience and alignment of program focus and philosophy. Other suggestions concerned widespread marketing efforts including print, online, and social networking websites. One respondent argued that in order to improve recruitment, awareness of epilepsy needs to be made as mainstream as possible.

"A multiple approach recruiting, including through the medical community and in a face to face way ought to be used to involve people in self management. Make it more of, less of an orphan, and more of an activity that seems more mainstream."

-Consumer Ombudsman, Inpatient Health Plan; person with epilepsy

There is no one-size-fits-all approach (12)

A general theme that emerged from several respondents was that no one approach will work for everyone and it is important to know an intervention's audience and tailor it appropriately. Differences to consider include age, developmental stage, cognitive ability, cultural differences, regional variances, the spectrum of epilepsies, and individual comfort levels, preferences and needs.

“Making it specific to the people or persons that you're talking to because, again, adolescents have different needs than, you know, older adults do, and I think you just have to take all that into consideration because interventions only work when the people who are engaged in them can see the benefits out of it.”

-Professor of Nursing

Intervention planners need to recognize these differences and design an intervention that focuses on a specific group with many shared similarities, and participants should be given choices so they can decide what will work best for them.

Fostering Peer Interaction and Support (8)

The importance of interventions that bring people with epilepsy or their caretakers together was emphasized by several respondents. People—in some cases people who are quite isolated—can see that they are not alone; group interactions can normalize feelings and experiences. It is important to allow for community building so that people can share similar problems as well as possible solutions, and receive support from one another.

“They don't see other people with epilepsy, so building that connection and seeing other people like them and sharing their issues, I think, is critical to have that connectedness to other people.”

- Professor, Health Behavior and Health Education

One respondent recommended that an infrastructure be put into place to support a long-lasting social network. Another talked about the value of connecting individual families with each other so that, for example, a family with experience with the ketogenic diet can share experiences with a family who is considering the diet. The less experienced family benefits from the other's wisdom, and the family with experience has the opportunity to connect with others and feel good about helping. Another recommendation was to utilize social networking sites such as Facebook (www.facebook.com) to promote connection and mutual support.

One respondent warned of the dangers of peer support if no one with medical expertise is present, because participants can mislead each other with inaccurate information.

Other (5 or less)

- Address depression and anxiety (5)
- Use a theoretical framework (4)
- Offer follow-up or multiple encounters (4)
- Involve family members (4)
- Setting is an important consideration (4)
- Test several strategies and review past research (4)
- Address using many strategies and formats (4)
- Be community based (3)
- Early intervention is important (3)
- Educate the general public (3)
- Include expert medical speakers (3)
- Offer remote participation options (3)
- Address transportation barriers (3)
- Address how it affects people differently (2)
- Back off over time (2)
- Keep it uncomplicated and avoid jargon (3)
- Model after self management interventions for other diseases (2)
- Involve nurses (2)
- Involve school systems (2)
- Address myths (1)
- Allow for flexibility to change formats (1)
- Train staff in crisis management (1)
- Educate neurologists (1)
- Consider small group size (1)
- Focus on desired outcomes (1)
- Give people with epilepsy choices (1)
- Involve the local Epilepsy Foundation affiliate (1)
- Involve the many people who help people with epilepsy (1)
- Involve people with epilepsy in planning the intervention (1)
- Funding is an important issue (1)
- Include access to legal assistance (1)
- Track long-term outcomes and feedback (1)
- Incorporate motivational interviewing (1)
- Incorporate peer education (1)
- Assist people without insurance (1)
- Include as much personal interaction as possible (1)
- Send regular newsletters (1)
- Determining the scope of targeted behaviors is important (1)
- Translation from research to practice is important (1)
- Aim to enrich the lives of people with epilepsy (1)

Key Stakeholders

15. *When planning an intervention to promote self management for people with epilepsy, who are the **key stakeholders** who should be at the table? (not actual individuals; representatives of certain organizations, agencies, professions, etc)*

Health Care Providers or Clinicians (71)

The most common stakeholder, identified by about seventy percent of respondents, was the health care provider or clinician. Most respondents listed specific professions, the most frequently cited being nurses. Physicians, neurologists, and epileptologists were other common responses. Some people identified health care providers by their care level: primary, secondary, or tertiary, and about an equal number of people mentioned primary care clinicians as opposed to specialists. A handful of respondents identified established epilepsy centers as key stakeholders.

Those who identified nurses often specified those with experience in epilepsy, nurse practitioners, epilepsy nurse specialists, advanced practice nurses, nurse clinicians, and nurse educators.

“An epilepsy nurse, and she kind of gets to know all the families... it’s a combined mindset of social worker, nurse, and clinician person.”

-Pediatric Neurologist

“An epilepsy nurse specialist, they’re fabulous... they’re absolutely fabulous. They play a key role.”

-Pediatric Neuropsychologist

Few respondents commented on the reasoning behind their selections. Some discussed the importance of getting buy-in from physicians and the difficulty of getting them involved. One respondent advised that no more than one neurologist be at the table due to their “expert” status and resulting inequity in power.

“A neurologist, but only like one... they tend to be the power broker as well... they don’t really know about communities, they know about neurology...”

-Director of an epilepsy organization in Australia; personal experience with epilepsy

People with Epilepsy (60)

Almost two thirds of respondents identified people with epilepsy as key stakeholders in the planning of an intervention. Recommended were high functioning and thoughtful individuals with epilepsy--people who have lived with and dealt with the disorder.

“An individual themselves or a family member. We’ve done a number of these where we include patients and/or families; they’re always our best source of information.”

- Clinical Nurse Specialist in an epilepsy program

Respondents also recommended individuals that represent the target population in more ways than having epilepsy; for example, if the target population is low income, poorly educated people with intractable epilepsy, a person with these characteristics should be involved in the planning. One respondent suggested working with support groups as an effective way to involve people with epilepsy.

Family Members or Caregivers (56)

More than half of respondents said that family members and caregivers are indispensable stakeholders in the planning stages of an epilepsy self management intervention. Most of the respondents who identified people with epilepsy also identified their caregiver, families, and even friends. For children with epilepsy, including parents or other caregivers was seen as essential since parents were primarily responsible for what is considered self management among adults.

It was clear from the comments, however, that even when planning an intervention for independent adults with epilepsy, respondents considered family members and friends as key stakeholders with valuable perspectives to contribute.

“Definitely the immediate family, spouse, any of the caregivers, people that are in close contact with the person on a pretty frequent basis, caregivers, loved ones, close relatives that just spend a lot of time with the person having epilepsy.”

-Executive Director of an Epilepsy Foundation affiliate; parent of child with epilepsy

“I think caregivers are another important because I think sometimes people with a disease are afraid to disclose issues or don’t want to share issues, but the caregivers or their significant others sort of see it happening or evolving—they’re there and can tell you the issues that they’re dealing with.”

- Professor, School of Public Health

One respondent warned, from experience, that some family members tend to focus only on the issues most relevant to their own family and would need to be advised or reminded to represent more than their own issues and speak on behalf of more global experiences.

Social Workers and/or Case Managers (42)

Social workers and case managers were frequently identified in order to represent care coordination issues and psychosocial issues. Included in this category are those who help people with epilepsy through special assistance programs and those who provide counseling, including cognitive behavioral therapy. There is some overlap between this and the “mental health professionals” category because several respondents identified social workers without specifying the type of services they had in mind.

“A counselor who understands the disorder and vulnerability.”

*-Epilepsy Services Specialist for an Epilepsy Foundation affiliate;
person with epilepsy*

“...that might include some cognitive problems and dealing with mental retardation, families dealing with mental retardation, so people like that, so social workers, and all the, all the administrative people in our government systems that deal with that.”

-Physician of patients with epilepsy

Epilepsy Foundation of America and Affiliates (36)

Over a third of respondents included the Epilepsy Foundation of America and/or its local affiliates in their list of key stakeholders. The local affiliates support people with epilepsy on a daily basis, are well connected to resources, and can often provide strong representation from the local epilepsy community.

“I also think that, you know, organizationally, I think like the Epilepsy Foundation, they tend to have a pretty strong foothold in the community of people who have epilepsy and other seizure disorders.”

-Physician Assistant in Neurology

Community Agencies and Organizations (32)

Another third of respondents discussed the need to include, in general, community agencies and organizations that provide services for people with epilepsy. Several people stressed the importance of including a diversity of agencies and services and not limiting representation to just one organization.

“I would hope that the Managing Well group doesn’t look at just one stakeholder or one agency as the one who speaks to everybody because the most important is the person with epilepsy, so I want to have people who can speak to that issue, and then those who can help disseminate and all these different agencies have different ways of reaching people.”

-Epilepsy Nurse Specialist; Research Specialist; person with epilepsy

Not only organizations that deal with epilepsy should be represented; since addressing epilepsy

requires a multidisciplinary approach, stakeholders need to be multidisciplinary as well. Suggested organizations and agencies included independent living centers and other organizations that assist people who also have other conditions such as cerebral palsy or mental retardation, disabilities groups, patient representation organizations, groups with experience in planning and implementing self management programs, the Epilepsy Therapy Project, Epilepsy Action, advocacy organizations, United Way, employment assistance services, community service organizations such as Lion's Club or Eagles, community counseling agencies such as Catholic Social Services, those involved in the self-help movement, epilepsy.com, seizuretracker.com, housing support, and transition committees.

One respondent argued that it is important to include from organizations the representatives who do the ground level work and have first-hand knowledge of the issues people face.

“Community organizations like ours, and their educators and managers, as well, not just their CEO, like their workers, because that is what often happens too, like their CEO turns up rather than the actual people that do the work, who know what people really need, the CEO doesn't necessarily know that.”

-Director of an epilepsy organization in Australia; personal experience with epilepsy

Mental Health Professionals (29)

Nearly one-third of respondents said either a mental health professional in general or identified specific types of such professionals, with the most common being psychologist. School psychologists, neuropsychologist, and pediatric and geriatric psychologists were also identified.

Psychiatrists or neuropsychiatrists, specifically those who specialize in epilepsy, were also identified, though one respondent questioned how realistic that would be. Some respondents discussed the need for counselors or professionals skilled in individual or group therapy. A respondent suggested including the Pre-admission Screening, the agency that decides if somebody has developmental disability and which services are available to them as well as a representative from the mental health board.

Teachers and other School Personnel (21)

Several respondents identified representatives of the school systems as important stakeholders. Specifically, teachers and school nurses were mentioned most frequently. School psychologists, guidance counselors, and special education teachers or leaders were also identified. Some respondents did not choose specific professions or representatives, but said that elementary and secondary schools and colleges as institutions should be included as a key stakeholders.

Other (10 or less)

- Developmental Disabilities Community Representatives (10)
- Community members (9)
- Employment services or vocational rehabilitation (5)
- Health educators (7)
- Researchers (7)
- Epilepsy advocate (6)
- American Epilepsy Society representative (6)
- Insurance or health plan representative (6)
- Public health professionals (6)
- Depends on intervention or audience (5)
- Funders (5)
- Hospital or health care system representative (5)
- Rehabilitation counselor, occupational therapist (5)
- Pharmacist or pharmacologist (5)
- Self management intervention experts (5)
- Business leaders (4)
- Church or spiritual leaders (4)
- Employers (3)
- Facilitators of the program (3)
- Pharmaceutical company representative (3)
- Professional associations/organizations (3)
- Professionals working with target participants (3)
- Dissemination expert (2)
- Federal agency representatives (2)
- Managing organization representative (2)
- Minority group representative (2)
- Policy makers (2)
- Technology experts (2)
- Autism community representative (1)
- CURE representative (1)
- International League Against Epilepsy (1)
- Media (1)
- Recreation therapist (1)
- Expert Panels (1)
- Traumatic brain injury community representative (1)
- Translator/interpreter (1)
- Public transportation representative (1)

Scales and Measures to Assess Programs

16. Do you know of any **scales or measures** that you think are effective for assessing self management programs? If yes, what are they?

Only a small proportion of respondents recommended specific scales:

Scale	Outcome Assessed	Number of Recommendations
Quality of Life in Epilepsy Inventory (QOLIE 10, 31, and 89)	Quality of Life	6
Epilepsy Self-Management Scale (Dilorio)	Self Management	5
Pediatric Epilepsy Self-Management Scale (Austin, adapted from Dilorio)	Self Management	2
Goal Attainment Scale	Achievement of goals chosen by participant	2
Knowledge Assessment used in Sepulveda Epilepsy Program	Improved knowledge	1
Liverpool Impact of Epilepsy Scale	Impact of epilepsy	1
Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)	Depression	1
Symptom Checklist 90-Revised (SCL-90-R)	Psychological health	1
Stanford patient education model assessment tools (recommendation: adapt tools)	multiple	1
Tools to assess patient response to medical home model (American Academy of Pediatrics)	multiple	1
Washington Psychosocial Seizure Inventory (WPSI)	Psychosocial functioning	1
Quality of Life in Epilepsy Inventory for adolescents (QOLIE-AD-48)	Quality of Life	1

Many respondents, however, had suggestions for outcomes that should be measured:

Outcome Assessment Suggestions (no scale recommended)	Number of recommendations
seizure control	14
quality of life	11
practice of self management skills	7
improved knowledge	7
mood/depression	6

Outcome Assessment Suggestions (no scale recommended)	Number of recommendations
compliance	5
self-efficacy and self reliance	5
goal attainment scaling	2
lifestyle	2
satisfaction with life	2
stigma	2
treatment tolerance	2
family effectiveness	1
health care utilization: ER and unscheduled visits	1
outcome expectations	1
patient satisfaction	1
post surgical outcomes	1
safety	1
social support	1

Quality of life was frequently recommended, but two respondents discussed that quality of life should not be measured because it is too broad and vague. A few respondents stated that the selection of assessment tools would vary greatly depending on the intervention, its target population, and objectives.

“I can’t answer the question without knowing a little bit more about the self management programs, you set them up, and depending on which you are focusing on they will have specific foci and objectives, and those objectives will inform the scales or measures that you then choose at the outcome or measures.”

-Professor of Medical Sociology

Dissemination

17. How should successful interventions be disseminated?

Note: *It was clear that this question was interpreted in different ways. Some respondents discussed ways to disseminate information directly to people with epilepsy and their families, whereas others discussed how a program or intervention proven to be successful could be disseminated to allow for implementation on a large scale. When possible, interviewers clarified that this second interpretation of the question was preferred.*

Preface

It is important to note that respondents strongly advised utilizing a combination of strategies so that a program can reach as many people as effectively as possible. The mixture of methods and materials should contain information that is digestible, applicable, appropriate for the audience it intends to reach, and addresses the various ways individuals gather and process knowledge. Multiple mechanisms were suggested: epilepsy and professional organizations, peer-reviewed literature, conferences and meeting presentations, training workshops, presentations, provider-to-patient communication, printed materials, online, television and radio shows, advertisements, public service announcements, newspaper articles and advertisements, support groups, and word of mouth.

The Epilepsy Foundation of America and Affiliates (44)

About forty five percent of respondents identified the Epilepsy Foundation of America (EFA) and its network of affiliates as an effective conduit for dissemination. Effective programs can be disseminated from the EFA to its affiliates in a variety of ways because of the many resources that the national office has at their disposal. Examples of such include: online information via the EFA website, PDF files, email list-serves to the affiliates, mass mailings, presentations and training workshops at meetings, conferences, and forums, fundraisers, and support groups. Furthermore, because of its reputation and credibility, the EFA has access to traditional forms of media that lend themselves well to information distribution such as newspapers and other publications, television, and radio.

Online (33)

A third of respondents included the Internet in their dissemination suggestions for reaching both professionals and people with epilepsy and their families. The Internet can be a fast and relatively inexpensive way to share information and tools; publishing in peer-reviewed literature often takes longer than a year. The Internet can be used to post tools and

information, conduct web-based presentations, blogs, and chats. It is important that online resources be posted in such a way that they are picked up by search engines such as Google so that they are easily accessible. Some respondents discussed that while the Internet can be quite effective for some people, it is important to use other methods for those who do not have easy online access, pointing to groups such as the elderly and those in a low socioeconomic class.

In addition to using the Internet in general, respondents frequently recommended disseminating through epilepsy.com and the Epilepsy Foundation of America's website.

Health Care Providers (27)

Health care providers such as physicians are sometimes the only professionals with whom people with epilepsy have contact, and their recommendations hold considerable sway with patients. Accordingly, more than a quarter of respondents recommended disseminating self management programs through health care providers. In addition to working through the professional organizations, clinicians can be reached through peer reviewed publications and professional journals. Several respondents suggested reaching out to comprehensive epilepsy programs and other well-known epilepsy centers. One respondent recommended that materials be made available in safety-net or free-care systems due to the fact that these providers typically care for underserved and undereducated patients.

In terms of relaying information to epilepsy patients, there are several strategies that respondents discussed. Suggestions included having information available in the form of a checklist for providers, brochures, posters, or newsletters at the provider's location. This can include primary care and neurologists' offices, hospitals, tertiary care facilities, regional epilepsy treatment centers, or a pharmacy. Some respondents recommended that clinicians refer patients to programs that exist outside the clinical setting, whereas others suggested that providers articulate the information to the patient directly and give them simple educational materials such as a pamphlet.

Professional Organizations (18)

Almost twenty percent of respondents recommended the American Epilepsy Society (AES) as an effective mechanism for program dissemination because of its relationship with key professionals who have an express interest in epilepsy. Akin to the EFA's ability to communicate information nationally, the AES utilizes many of the same strategies to disseminate information to health care professionals. These include: online materials, PDF files, mailings, annual meetings, professional presentations, and training workshops. One respondent did warn that in order for these training workshops to be effective, barriers to participation such as high prices must be mitigated, and a few respondents encouraged offering continuing education credits as an incentive.

Other professional organizations that were recommended:

- American Academy of Neurology (1)
- American Association of Neuroscience Nurses (1)
- American Medical Association (1)
- American Neurological Association
- Boards of Nursing (1)
- Child Neurology Society (1)
- National Association of Social Workers (1)

Reaching Patients with Epilepsy Directly (17)

Several respondents agreed that a comprehensive dissemination strategy must also directly reach the consumers. Such an approach can be seen as empowering for patients because a person with epilepsy can learn about a program and then encourage a clinic or organization to offer the program, thus creating demand from the bottom up. One respondent's argument for directly reaching out to consumers is that too many people do not have consistent access to health care, and dissemination through health care professionals would not reach these individuals. This respondent also suggested that to effectively reach a broad range of patients, public health announcements either via radio, mailings, or television, would be most appropriate. Others suggested the usage of public service announcements. A respondent with considerable program recruitment experience pointed out that while most professionals are influenced by quantitative outcome data, lay people respond better to testimonials.

Journals and other Academic Paths (13)

Peer reviewed publications such as the journal *Epilepsy and Behavior* were seen as important, but not sufficient, routes of dissemination. Other academic paths such as lectures at universities and colleges were also recommended.

Government (11)

About ten percent of respondents discussed governmental options for disseminating information. One of the recurring responses included using the Centers for Disease Control and Prevention (CDC) as a conduit for spreading information on effective programs. In a similar vein, some suggested using the CDC's Managing Epilepsy Well (MEW) Network. One person cited that the National Institutes of Health (NIH) would be an ideal organization to disseminate information as well. Other responses regarding government involvement included using state and local health departments to spread information.

What to include in dissemination (7)

In addition to discussing ways to disseminate information, some respondents provided advice on what exactly should be disseminated. Some suggestions were to include the evaluation data with outcomes attained, and ideally show how the interventions can decrease costs. When disseminating a program, the complete package should be shared, with information on the cost of running the intervention, how to maximize access to the program, and how to recruit effectively. Others added that the intervention should be offered in multiple languages and formats. Lastly, one respondent advised providing grant funding for implementation.

Other (5 or less)

- Epilepsy and Patient Organizations (4)
 - Epilepsy organizations
 - Epilepsy.com
 - Patient organizations
 - International League Against Epilepsy
- Insurance companies (3)
- Pharmacies (2)
- School systems (2)
- Community organizations and social service agencies (2)
- Disability organizations and agencies (1)
- Developmental disability organizations and agencies (1)
- Case management networks (1)
- Mental health boards (1)
- Groups that address self management of other chronic diseases (1)
- Develop marketing campaign (2)
- Examine dissemination and diffusion of innovation literature (1)
- Promote effective models (1)

Helpful Services

*18. Outside of formal self management programs, what other **services** are most helpful in promoting effective self management of epilepsy?*

Social Support Groups/Networks (37)

The top response to this question, identified by more than a third of respondents, concerned services and opportunities that connected people with epilepsy and their families with others who have the disorder. Both virtual and in-person support groups for people with epilepsy and for parents of children with epilepsy can be beneficial by showing people that they aren't alone, sharing successful management techniques, and providing compassion, encouragement, and support through challenging times. Such groups can also be a means of information dissemination; for example, support groups may feature guest speakers on how the brain functions, medication issues, or other topics of interest.

Respondents also recommended social events to bring people together, and several saw great benefit in providing camps for children with epilepsy, or retreats for adults. Taking on the role of mentor to another person with epilepsy can be beneficial to both the mentor and mentee, and some respondents described the benefits of connecting people who have had a specific treatment, such as surgery, with those who are considering the same treatment. Another related suggestion that could be useful for the newly diagnosed, would be memoir-like documents written by people with chronic disease that describe how they came to terms with living with the condition.

Social Service Organizations and Professionals (36)

According to over a third of respondents, social workers, case managers, and social service agencies are some of the most helpful services in promoting effective self management of epilepsy. About half of these respondents specifically referred to the Epilepsy Foundation affiliates. Social service organizations, especially if their focus is epilepsy, can provide a range of services including education and information, help navigating other social services, emergency medication programs, advocacy services, support groups, case management, referrals, and one-on-one consultation. Individualized services such as tailored education, support, and counseling can focus on specific issues and direct people who may otherwise feel bombarded by an overwhelming amount of information.

Ancillary services not specific to epilepsy such as respite care for parents of children with epilepsy can be helpful as well. Social service organizations that focus on other conditions such as cerebral palsy can support people with a dual diagnosis.

Education and Informational Materials (28)

Nearly thirty percent of respondents discussed services and resources that build a person's understanding of their disorder and ways to manage it. Traditional educational materials and methods such as newsletters, books, pamphlets, clinic-based patient education, presentations, seminars, retreats, and conferences were identified, but the most commonly discussed source was the Internet. While a few respondents noted that not all information on the Internet is useful, all said there were some websites that provided good information; Epilepsy.com was recommended by several. The Epilepsy Foundation of America and its affiliates was another frequently cited source of information.

Health Care Centers, Hospitals, and Providers (20)

Services provided by health care providers and their affiliated institutions were cited as helpful, if not critical, to promoting effective self management. Comprehensive epilepsy centers were seen as vital resources especially important for people with intractable seizures.

“If you're still having seizures, you should get earlier access to knowing what you're living with, you know, proper diagnosis, proper treatment, and maybe you can prevent all the other complications and a lot of the need for the self management, so I think that's probably critical to all of this.”

-Epilepsy Nurse Specialist; Research Specialist; person with epilepsy

In addition to proper diagnosis and treatment, health care workers and institutions provide education and information that supports effective management; as one respondent put it, “a good clinical relationship is critical.” Respondents identified primary care and specialist physicians, social workers, nurse practitioners, and epilepsy specialist nurses as important sources of information and feedback. Some respondents described educational materials and resources produced by hospitals and clinical systems that send out reminder materials and encourage questions by phone.

Services that help people find and access the medical care they need, including local neurologists, low-cost clinics, and epilepsy centers were also considered important in promoting the self management process.

Mental Health Services (18)

Nearly twenty percent of respondents discussed mental health services such as counseling by a licensed social worker, psychologist, or psychiatrist, both for comorbid mood conditions and to give people the chance to discuss psychosocial issues that they may not be comfortable

speaking about in a group setting. Access to such services, however, is not always easy; insured individuals may not have coverage for mental health, and low cost services like county mental health often have very long waiting lists.

Vocational (16)

Vocational services, particularly vocational rehabilitation, were cited by several respondents. Specific state programs and those that are part of social services agencies such as the Epilepsy Foundation affiliates were referenced, though some respondents described the difficulties in obtaining government vocational services that have strict eligibility criteria and require potential recipients to jump a daunting number of hoops. A few answers also mentioned referral programs, training classes, and even informal employment networks to help people find and maintain work. One respondent discussed how vocational assistance needs to advise people on how to handle disclosure issues in the workplace.

Financial Assistance (13)

Most references to financial assistance services had to do with access to health care and medications. Respondents identified social security, disability, patient assistance programs, state waiver programs, and health insurance as important services for people with epilepsy. One respondent discussed affordable housing, and another cited the need for funds for education and recreation.

Other (10 or less)

- Public awareness raising (10)
- Transportation (10)
- Advocacy (6)
- People with epilepsy--mentors and models (5)
- Volunteer and leadership opportunities (4)
- Seizure diary, log or tracker (4)
- Depends on individual needs and stage of life (3)
- Legal assistance (3)
- Religious organizations (3)
- Nutrition services (2)
- Pharmacist (2)
- Cognitive rehabilitation (1)
- Support from family (1)
- Healthy lifestyle promotion services (1)
- Kindness in the world (1)
- Support from individual's personal community (1)

- Respite care for parents (1)
- Equipment for safety in the home (1)
- Safety and epilepsy action plans (1)
- School nurses (1)

Existing Programs

19. Do you know of any (other) epilepsy management programs?

Note: The interviewer typically explained that this project has identified self management programs published in peer reviewed literature and that the purpose of this question was to identify any programs that may not be in the literature.

No Knowledge of Programs (39)

Over a third of respondents said that they did not know of any epilepsy self management programs.

Epilepsy Foundation Programs and Services (29)

Nearly thirty percent of respondents discussed programs and services provided by the Epilepsy Foundation of America (EFA) and its affiliates. Three specific programs from the EFA were identified: Helping Other People with Epilepsy (HOPE), and two programs for teens and young adults, Take Charge and Youth Council. Aside from formal programs, affiliates typically offer a number of services that contribute to effective self management, including but not limited to group education sessions, retreats, support groups, one-on-one patient education, employment programs, referrals, advocacy, written and online education materials, patient assistance programs, and education efforts in the community. In Florida, the state government funds more comprehensive epilepsy services, many through the local EFA affiliates, but no formal self management programs were identified. There is a lot of variety in what programs each affiliate provides and how they offer them, and the processes and outcomes of most of these services have not been formally researched.

Clinicians and Centers (10)

Several respondents pointed out that many clinicians such as doctors, nurses, and social workers integrate self management into their clinical practice on a daily basis, and while much of this work is not a formal program per se, it is important to study their work and its outcomes. Comprehensive Epilepsy Centers and other formalized epilepsy programs are more likely to have the resources to provide programs or other services that support self management, and some respondents identified specific clinics that may have programs, such as the Cleveland Clinic, Children's Hospital of Philadelphia, UCLA, Minnesota Comprehensive Epilepsy Program, Minnesota Epilepsy Group, Harborview Epilepsy Center, Seattle Children's, University of Southern California, and Mayo. The Andrews-Reiter Epilepsy Research Program in California is

a treatment program that takes a behavioral approach to epilepsy care which thoroughly integrates self management practices into the treatment plans. One respondent identified a ketogenic diet group at the local children's hospital.

Internet (6)

The information available at the site called epilepsy.com, funded by the Epilepsy Therapy Project, was cited by some respondents. Also cited were the website for the Epilepsy Foundation of America and seizuretracker.com, an online tool for tracking seizures, medication dosing, and appointments. One respondent discussed the utility of other electronic formats such as thumb drives and Google Health subscriptions for people with access.

International Work (5)

Respondents recommended a number of international clinics and organizations that may offer programs, including the International League Against Epilepsy, Epilepsy and Seizure Education Program of British Columbia, Epilepsy Australia, Bielefeld Epilepsy Clinic in Germany, and the Expert Patient Program in the United Kingdom.

Nonprofit Organizations (5)

A few nonprofit organizations other than the Epilepsy Foundation and its affiliates were reported as possibly providing self management programs: the Epilepsy Education Association, CURE, the Abilities Network in Maryland, and People, Inc. One respondent said that there are a large number of such organizations in the country, and their services can vary from basic education to more comprehensive services such as medical management.

Chronic Disease Self Management (3)

Some respondents referred to programs and services that are not specific to epilepsy but aim instead for the self management of chronic diseases in general. Those listed included a chronic care hospital for children in Virginia, the Flinders Program in Australia, and the Patient Expert Program in the United Kingdom.

Pharmaceutical and Medical Device Companies (3)

Pharmaceutical companies and Cyberonics, the company that sells the Vagus Nerve stimulator, may offer programs and services that support self management; three respondents identified these companies but did not specify a particular program.

Others (1 response each)

- Camps for kids
- Search the gray literature—conference abstracts and presentations—because it sometimes takes years to publish a paper
- The Illness Management and Recovery Curriculum: a recovery-based model from the United States Psychosocial Rehabilitation Association; uses evidence-based practices for mental illness; offered through the State of Minnesota

Additional Suggestions

*19. Are there any **topics, or questions I have not asked**, that you think are important for us to discuss or for me to ask of others?*

No suggestions (31)

Nearly a third of respondents volunteered nothing further to discuss and did not have suggestions for the improvement of the interview.

Design program to address issues specific to certain groups (11)

Just over ten percent of respondents said that despite the challenge of doing so, self management interventions need to be designed in a way that addresses issues specific to the various populations of people with epilepsy, making programs available in a manner that is useful for all cultural and educational groups. In order to do this, some suggested developing a series of modules that vary in sophistication to address the variability inherent in epilepsy. For example, respondents said that therapy that focuses on one's future and life goals should be incorporated into interventions for people with epilepsy who are in their twenties and thirties, and young people with epilepsy should be surveyed to discover what they feel would be most useful to them in an epilepsy program.

Respondents also mentioned that the materials and methods of an intervention must address memory problems commonly seen among people with intractable epilepsy. The mentally retarded, who often cannot effectively communicate information such as medication side effects that would help in their treatment, also need tailored programs.

Other respondents focused on teenagers, noting that the transition from adolescence to adulthood is a huge issue for families with teens who have epilepsy. Respondents suggested that teens be engaged using an electronics-based, unique approach.

Practicality needed for a pilot (6)

Less than ten percent of respondents stressed the need for practicality in the design, dissemination, and implementation of an epilepsy self management intervention. To design a program that would be so costly to implement or require such highly trained personnel that they are not readily available would prove unhelpful and impractical. Other respondents suggested that focus should be placed on the desired outcomes of any intervention in development so that the approach to implementation can be simple, practical, and more

effective. Cost effectiveness should be incorporated into the interventions so that the program has a greater chance of being funded; for example, show the extent to which attending the program could lower healthcare costs for the individual, state or nation as a whole.

Gender issues (4)

A small proportion of respondents brought up gender issues as another topic to keep in mind when planning interventions. Some self management needs to be specific to women's and men's issues. Women with epilepsy have serious concerns and risks due to the hormonal shifts at menstruation, being pregnant, breastfeeding, and the hormonal changes around menopause, all of which can affect seizure frequency and severity, as well as have an impact on comorbid disorders that may occur with their epilepsy. Respondents suggested that researchers explore the unique impact of epilepsy on women, men, or couples in deciding whether to have a family.

“The women of childbearing age, that I mentioned before, pregnant women, require a very special follow-up because the majority of drugs are teratogenic, or cause congenital malformation in the fetus.”

*-Director of Medical Services at a Children's Hospital;
has family member with epilepsy*

Medication resources (4)

A few respondents suggested that research be done to ask people what they think about the issue of medication access. Healthcare reform is a critical national debate that will affect most, if not all, people with epilepsy. Some suggested research questions were which resources respondents use and how they gain access to and utilize existing resources.

Address stigma (4)

Less than five percent of respondents mentioned that because one of the biggest issues with epilepsy is stigma, including a segment on how to break down the barriers of stigma would be useful in any self management curricula. One respondent mentioned that the last good work done on stigma was published in 1963 by Erving Goffman.

Using the word *intervention* (3)

Three respondents mentioned that the word *intervention* itself is misleading and should be used with caution and thought. Respondents thought the term was “emotionally wrought,” and

a “loaded word” that has “some negative connotations.” One respondent said that despite this, the word was appropriate in this context; however, people with epilepsy, as well as some professionals, might consider it insensitive or offensive.

Cultural competency (2)

A couple of respondents mentioned the need for cultural competency and pointed out that the interview was lacking in any racial or ethnic differentiation, although one mentioned that doing so would make it an entirely different study.

“People need to recognize the need for cultural competency. We need to be sensitive to the various ethnic and other cultural groups that we serve, that they don’t always have the same basic information, that we can’t make assumptions about where they’re coming from, that we recognize that they may look at epilepsy from a very different vantage point, and that we need to make accommodations for that.”

- Physician Assistant in Neurology

Driver’s license and insurance (2)

Two respondents said that the interview should have included driver’s license laws and insurance as a topic under consideration. The driver’s license laws cause many problems in treatment because some patients may not report their seizures if they are afraid their licenses will be taken away. There is trouble on the legal end of things as well: some insurance companies and even a state Department of Motor Vehicles will deny a license or insurance to people if they indicate they have epilepsy, even if their seizures are completely controlled.

Elderly population (2)

Some respondents said that the elderly are an important topic of discussion when it comes to creating self management programs. The elderly are a vulnerable population, with the highest incidence of epilepsy in the U.S., who also have special issues such as the need for multiple medications and the progressive decline of bodily functions. Respondents suggested that we need to address the elderly differently than other populations because of these issues. Additionally, the elderly may view the disorder differently than younger people, and they may view changing medications with more suspicion.

Head injuries (2)

Two respondents mentioned that a lot of people in the armed services are returning from active duty with head injuries, and they often need counseling and treatment for post-traumatic stress disorder before the vulnerabilities brought on by epilepsy can be addressed.

Medication issues (2)

Insurance companies in many cases will no longer cover name brand medications, and people with epilepsy are afraid to switch to generics. Respondents suggest that future research ask key informants how they make sure people get the medications they need.

Advice on interview content and process (1 respondent each)

- Ask more specific questions
- Ask respondents how they define their philosophy of self management because the definition is loose and people will have different ideas, especially across disciplines, of what self management means
- Ask who would be the main support people enabling a person to self manage effectively
- Ask about how patient questions about alternative treatments such as chiropractic treatments, herbs, and vitamins should be answered
- Ask about how to involve family members without contributing to dependency
- Ask respondents what are the mediators (i.e., mood, self efficacy, stigma) to outcomes so that the clinical and research community knows what is going to affect the outcomes of a self management program
- Ask how schools are getting Diastat to children in a timely manner
- Ask about the different management strategies for varying types or degrees of seizures; care will vary drastically between individuals
- Tinker with the question about behavioral objectives for clarity
- Examine the entire system that encompasses epilepsy work
- In the interview, incorporate how people diagnosed with epilepsy and/or their parents go through a grieving process because they are experiencing loss regarding future options such as career choices
- Offer respondents the option of completing the survey in written form so that people could spend more time on certain questions and not feel they are wasting the interviewer's time trying to think about the best answer

Other (1 respondent each)

- It is very important to try and build a self management program for patients in the epilepsy community because self management is so multi-faceted and clinicians do not have the time needed to devote to it
- People with psychosocial problems should be told to go to a psychologist, but since so many don't go, other supports need to be put in place
- Not all epilepsy centers discuss all treatment options, such as VNS or the ketogenic diet, with patients, but they should

- Exposure to and use of the arts as art therapy is effective and cheap; individuals have been shown to get better more quickly by using art therapy
- Biofeedback can be useful during initial treatment to help people learn how their brain works and changes with mood states, but it has been over utilized and creates a dependency of patients on the biofeedback instead of using their own self-awareness
- Address fear around diagnosis
- Seizure diaries are useful tools if they are used, but it is difficult to get people with low income or low IQs to use them; they are most successful when used by parents and caregivers
- Motivation, esteem-building, and encouraging self-responsibility are important to self management and often not addressed enough
- A self management program should include content about Sudden Unexplained Death in Epilepsy (SUDEP)
- When assessing research participants, use face-to-face methods, strong follow-up, and incentives to return surveys
- People with epilepsy need to realize the urgency of finding a treatment that controls seizures in order to prevent a cycle of problems; those diagnosed later in life need to be targeted
- Employers are very important areas to target in terms of keeping stigma out of the workplace and finding employment for people with epilepsy

Appendix A: Key Informant Perspectives Interview Questionnaire

Contributing to Managing Epilepsy Well Project

ABOUT THE RESPONDENT

1. Confirm name, title(s), organization, email address
2. A. Are you Hispanic, Latino, or of Spanish descent?
B. How would you describe your race?

American Indian/Alaska Native
Asian
Native Hawaiian or Other Pacific Islander
Black or African American
White
More Than One Race
Unknown or Not Reported

3. Please provide me with some background about your experience with or knowledge of epilepsy self management.
consider: profession, roles in studies, committees, direct contact with people with epilepsy, years of experience

RESPONDENT OPINIONS ABOUT EPILEPSY SELF-MANAGEMENT

The next set of questions will ask for your opinions about epilepsy self management. When using the term self-management, we mean 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.

1. What would you say is the **most significant challenge people with epilepsy** face in managing their condition?
2. What is the most important thing a person with epilepsy **needs to be able to do** to manage his or her condition?

3. Among people with epilepsy, what **subgroup of people are most in need** of an intervention to promote self management?

consider: patient with disease/caregiver, gender , age, income, education level, race/ethnicity, rural/sub/urban, seizure frequency and type, presence of co-morbid conditions

4. What do you think is the **greatest difficulty facing clinicians** in helping their patients with epilepsy better manage their condition?

5. What **type of clinicians are most in need** of an intervention to promote self management?

consider: profession, specialty, population clinician serves, years in practice

6. Aside from people with epilepsy and clinicians, **are there others** who should be targeted in an intervention to improve self management of epilepsy? If so, please describe them.

7. What **agency or organization** should manage epilepsy self management programs?

8. What is the most important **outcome** an epilepsy program can achieve?

9. What would you say are the top three the most important **behavioral objectives** for an epilepsy program to set for participants?

10. What are the common barriers to participation in an epilepsy self management intervention?

11. What can be done to reduce these barriers?

12. Of the work that seeks to improve epilepsy self management, is there a weakness or challenge that needs to be addressed? (beyond barriers to participation)

13. I'll read several pairs of different strategies that may be employed in promoting epilepsy self-management. For each pair, please tell me which one of the two you think is **more effective** in improving self-management of epilepsy. For some of these pairs, it may seem difficult to choose one over the other, so feel free to comment on why choosing one is difficult.

a. Clinical setting or community setting

b. Telephone or face-to-face

- c. Web-based or telephone-based
- d. Printed or electronic materials
- e. Group or one-on-one
- f. Weekly sessions or retreat
- g. Social worker or nurse specialist
- h. Physician or health educator
- i. Family or individual
- j. Case management or counseling
- k. Education or case management
- l. Self administered or facilitated
- m. Lay-led or professional-led
- n. Counseling or education

14. Is there anything else you'd like to recommend about intervention strategies?

consider: recruitment, setting, format, methods, staffing, theoretical frameworks

15. When planning an intervention to promote self management for people with epilepsy, who are the **key stakeholders** that should be at the table? (not actual individuals; representatives of certain organizations, agencies, professions, etc)

16. Do you know of any **scales or measures** that you think are effective for assessing self management programs? If yes, what are they?

17. How should successful interventions be disseminated?

18. Outside of formal self management programs, what other **services** are most helpful in promoting effective self management of epilepsy?

19. Do you know of any (other) epilepsy management programs?

20. Are there any **topics, or questions I have not asked**, that you think are important for us to discuss or for me to ask of others?

21. Could you recommend the names of up to three people who you think we should interview to better understand what is needed and what would be effective in the area of epilepsy self-management?

Appendix B: Comparison of Most Frequent Responses by Respondent Type

For seven survey questions, the top five most prevalent responses mentioned were examined to see if the percentage of respondents citing each theme varied considerably among the three major respondent profession types (clinicians, social service providers, and researchers) and by whether or not the respondent had personal experience with epilepsy (defined as a respondent who volunteered that he or she has epilepsy or has a child or other close family member with epilepsy). A chi-square test of homogeneity compared the groups to see if the proportion of respondents who mentioned a particular response differed by profession or by whether or not they had personal experience with epilepsy. Responses that differed significantly ($p < 0.05$) are reported in the findings below, organized by question.

1. *What would you say is the most significant challenge people with epilepsy face in managing their condition?*

Of the top five response themes to this greatest challenge question, only two varied significantly by respondent profession type: clinical care ($p < 0.0001$) and affording medications ($p < 0.018$). 88% of researchers cited clinical care issues as a greatest challenge compared to 56% of social service providers and only 22% of clinicians. Among clinicians, cognitive difficulties and compliance were among the top five responses. Affording medications was cited by 27% of social service providers, 10% of clinicians, and no researchers. Among researchers, gaining seizure control replaced affording medications in the top five.

Top Five Most Common Responses, all respondents and by respondent profession type

All Respondents (n=101)		Clinicians (n=41)		Social Service Providers (n=41)		Researchers (n=16)	
clinical care	48%	psychological effects	32%	clinical care	56%	clinical care	88%
psychological effects	26%	clinical care	22%	affording medications	27%	psychological effects	31%
stigma and lack of public understanding	20%	cognitive difficulties	20%	stigma and lack of public understanding	24%	stigma and lack of public understanding	25%
employment	15%	compliance with medical regimen	20%	psychological effects	20%	gaining seizure control	25%
affording medications	15%	stigma and lack of public understanding	15%	employment	15%	employment	19%

Of the top five response themes to this greatest challenge question, only two varied significantly by whether the respondent had personal experience with epilepsy: stigma and lack of public understanding ($p < 0.0057$) and affording medications ($p < 0.0625$).

Only 3% of those with personal experience cited stigma and lack of public understanding as a greatest challenge, whereas 27% with no personal experience did. Instead, cognitive difficulties was among the

top five cited by people with personal experience. Affording medications was cited by 27% of people with personal experience and by only 10% of those without; compliance replaced affording medication one of the top five responses among those with no personal experience.

Top Five Most Common Responses, all respondents and by whether respondent has personal experience with epilepsy

All Respondents (n=101)		Personal Experience (n=30)		No Personal Experience (n=71)	
clinical care	48%	clinical care	60%	clinical care	43%
psychological effects	26%	affording medications	27%	psychological effects	29%
stigma and lack of public understanding	20%	psychological effects	20%	stigma and lack of public understanding	27%
employment	15%	employment	17%	employment	14%
affording medications	15%	cognitive difficulties	17%	compliance with medical regimen	14%

2. What is the most important thing a person with epilepsy needs to be able to do to manage his or her condition?

Of the top five response themes to this question, only one varied significantly by respondent profession type: medication compliance (p<0.046). Medication compliance was the most frequently mentioned response from clinicians (46% of clinicians mentioned medication compliance), but it was mentioned by only 24% of social service providers and 19% of researchers. More researchers and social service providers mentioned the need to “understand their own condition” than those who mentioned medication compliance.

Top Five Most Common Responses, all respondents and by respondent profession type

All Respondents (n=101)		Clinicians (n=41)		Social Service Providers (n=41)		Researchers (n=16)	
medication compliance	32%	medication compliance	46%	understand their own condition	27%	understand their own condition	31%
understand their own condition	31%	understand their own condition	32%	medication compliance	24%	medication compliance	19%
accept the disorder	14%	understand and avoid their triggers	22%	accept the disorder	20%	have good relationship and communication with physician	19%
have good relationship and communication with physician	14%	access to medication	17%	have good relationship and communication with physician	17%	have social support	19%
access to medication	13%	accept the disorder	10%	be a self advocate	17%	accept the disorder	13%

Of the top five response themes to this question, none varied significantly by whether the respondent had personal experience with epilepsy.

Top Five Most Common Responses, all respondents and by whether respondent has personal experience with epilepsy

All Respondents (n=101)		Personal Experience (n=30)		No Personal Experience (n=71)	
medication compliance	32%	understand their own condition	32%	understand their own condition	36%
understand their own condition	31%	medication compliance	23%	medication compliance	30%
accept the disorder	14%	have good relationship and communication with physician	19%	accept the disorder	14%
have good relationship and communication with physician	14%	accept the disorder	13%	understand and avoid triggers	14%
access to medication	13%	access to medication	13%	access to medication	13%

4. What do you think is the greatest difficulty facing clinicians in helping their patients with epilepsy better manage their condition?

Of the top five response themes to this question, only one 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 and providing self management education were in the top five, and among social service providers, financial barriers replaced lack of supportive services as one of the top five most frequently cited responses.

Top Five Most Common Responses, all respondents and by respondent profession type

All Respondents (n=101)		Clinicians (n=41)		Social Service Providers (n=41)		Researchers (n=16)	
time limitations	36%	time limitations	37%	time limitations	39%	limited focus	38%
limited focus	25%	limited focus	22%	limited focus	22%	time limitations	31%
finding best course of treatment	11%	lack of supportive services	20%	accurate reporting from patient	17%	finding best course of treatment	19%
lack of supportive services	10%	financial barriers	15%	financial barriers	15%	keeping up-to-date medically	19%
patient does not follow care plan	10%	patient does not follow care plan	15%	finding best course of treatment	12%	providing self management education	19%

Of the top five response themes to this question about the greatest difficulty clinicians face, only one varied significantly by whether the respondent had personal experience with epilepsy: finding the best course of treatment ($p = 0.017$). Sixteen percent of respondents with no reported personal experience

with epilepsy mentioned finding the best course of treatment, whereas none of the respondents with personal experience did.

Top Five Most Common Responses, all respondents and by whether respondent has personal experience with epilepsy

All Respondents (n=101)		Personal Experience (n=30)		No Personal Experience (n=71)	
time limitations	36%	limited focus	32%	time limitations	41%
limited focus	25%	time limitations	26%	limited focus	20%
finding best course of treatment	11%	accurate reporting from patient	19%	finding best course of treatment	16%
lack of supportive services	10%	patient does not follow care plan	13%	lack of supportive services	14%
patient does not follow care plan	10%	keeping up-to-date medically	13%	financial barriers	14%

7. What agency or organization should manage epilepsy self management programs?

Of the top five response themes to this question, only one varied significantly by respondent profession type: the need for a team approach because no one agency or organization has the capacity to address all aspects of self management (p<0.007). Clinicians much more frequently expressed this idea (34%) when compared to social service providers (10%) and researchers (6%).

Top Five Most Common Responses, all respondents and by respondent profession type

All Respondents (n=101)		Clinicians (n=41)		Social Service Providers (n=41)		Researchers (n=16)	
Epilepsy Foundation	64%	Epilepsy Foundation	61%	Epilepsy Foundation	63%	Epilepsy Foundation	75%
hospitals, health systems, CEPs	40%	hospitals, health systems, CEPs	39%	hospitals, health systems, CEPs	41%	hospitals, health systems, CEPs	40%
government	20%	team approach	34%	government	24%	government	31%
team approach	19%	community connection	17%	social service agency	15%	community connection	13%
community connection	12%	American Epilepsy Society	15%	team approach	10%	team approach	6%

Of the top five response themes to this question about which agency or organization should manage programs, none varied significantly by whether the respondent had personal experience with epilepsy.

Top Five Most Common Responses, all respondents and by whether respondent has personal experience with epilepsy

All Respondents (n=101)		Personal Experience (n=30)		No Personal Experience (n=71)	
Epilepsy Foundation	64%	Epilepsy Foundation	61%	Epilepsy Foundation	66%
hospitals, health systems, CEPs	40%	hospitals, health systems, CEPs	38%	hospitals, health systems, CEPs	40%
government	20%	government	23%	government	19%
team approach	19%	team approach	23%	team approach	17%
community connection	12%	social service agency	13%	community connection	13%

8. What is the most important *outcome* an epilepsy program can achieve?

Of the top five response themes to this question, only one varied significantly by respondent profession type: quality of life ($p=0.039$). About the same percentage of clinicians and researchers mentioned quality of life (32% and 31%), but only 10% of social service providers cited quality of life.

Top Five Most Common Responses, all respondents and by respondent profession type

All Respondents (n=101)		Clinicians (n=41)		Social Service Providers (n=41)		Researchers (n=16)	
seizure control	28%	seizure control	46%	seizure control	34%	quality of life	31%
quality of life	22%	quality of life	32%	confidence / control	20%	seizure control	25%
confidence / control	20%	confidence / control	22%	quality of life	10%	improved self management	25%
independence	10%	independence	12%	independence	10%	confidence / control	19%
improved self management	10%	no side effects	12%	no side effects	7%	no shame or stigma	13%

Of the top five response themes to this question, none varied significantly by whether the respondent had personal experience with epilepsy.

Top Five Most Common Responses, all respondents and by whether respondent has personal experience with epilepsy

All Respondents (n=101)		Personal Experience (n=30)		No Personal Experience (n=71)	
seizure control	28%	seizure control	29%	seizure control	40%
quality of life	22%	confidence / control	29%	quality of life	24%
confidence / control	20%	quality of life	16%	confidence / control	16%
independence	10%	no shame or stigma	10%	independence	11%
improved self management	10%	no side effects	6%	no side effects	11%

9. What would you say are the top three most important behavioral objectives for an epilepsy program to set for participants?

Of the top five response themes to this question, only one varied significantly by respondent profession type: acceptance, attitude, and coping (p=0.002). Many more social service providers cited these psychological themes (41%) than either clinicians (10%) or researchers (13%). Instead, clinicians and researchers more frequently cited effective communication with physicians as an important behavioral objective.

Top Five Most Common Responses, all respondents and by respondent profession type

All Respondents (n=101)		Clinicians (n=41)		Social Service Providers (n=41)		Researchers (n=16)	
compliance / adherence	58%	compliance / adherence	61%	compliance / adherence	56%	compliance / adherence	50%
healthy lifestyle and trigger reduction	31%	healthy lifestyle and trigger reduction	34%	acceptance, attitude, coping	41%	healthy lifestyle and trigger reduction	25%
acceptance, attitude, coping	24%	communication with physician	22%	healthy lifestyle and trigger reduction	29%	understand epilepsy	19%
understand epilepsy	17%	understand epilepsy	20%	advocate for oneself	22%	organization of self and goal setting	19%
recognizing own triggers	16%	recording seizures accurately	12%	recognizing own triggers	17%	communication with physician	19%

Of the top five response themes to this question about behavioral objectives, none varied significantly by whether the respondent had personal experience with epilepsy.

Top Five Most Common Responses, all respondents and by whether respondent has personal experience with epilepsy

All Respondents (n=101)		Personal Experience (n=30)		No Personal Experience (n=71)	
compliance / adherence	58%	compliance / adherence	61%	compliance / adherence	57%
healthy lifestyle and trigger reduction	31%	healthy lifestyle and trigger reduction	35%	healthy lifestyle and trigger reduction	29%
acceptance, attitude, coping	24%	acceptance, attitude, coping	32%	acceptance, attitude, coping	20%
understand epilepsy	17%	understand epilepsy	19%	understand epilepsy	16%
recognizing own triggers	16%	keep appointments	19%	communication with physician	16%

10. What are the common barriers to participation in an epilepsy self management intervention?

None of the top five response themes to this question varied significantly by respondent profession type.

Top Five Most Common Responses, all respondents and by respondent profession type

All Respondents (n=101)		Clinicians (n=41)		Social Service Providers (n=41)		Researchers (n=16)	
transportation	53%	transportation	41%	transportation	66%	transportation	44%
psychological barriers	36%	psychological barriers	34%	psychological barriers	41%	unaware of program	31%
financial barriers	23%	financial barriers	20%	financial barriers	32%	time conflicts	31%
stigma	21%	cognitive issues	20%	stigma	27%	psychological barriers	25%
self management not valued or understood	16%	stigma	20%	lack of access to care	15%	self management not valued or understood	25%

Of the top five response themes to this question on barriers, none varied significantly by whether the respondent had personal experience with epilepsy.

Top Five Most Common Responses, all respondents and by whether respondent has personal experience with epilepsy

All Respondents (n=101)		Personal Experience (n=30)		No Personal Experience (n=71)	
transportation	53%	transportation	61%	transportation	49%
psychological barriers	36%	psychological barriers	42%	psychological barriers	33%
financial barriers	23%	stigma	29%	financial barriers	23%
stigma	21%	financial barriers	23%	stigma	17%
self management not valued or understood	16%	self management not valued or understood	16%	time conflicts	17%

Appendix C: Acknowledgements

Advisory Panel

The Center for Managing Chronic Disease and the Epilepsy Foundation of Michigan gratefully acknowledges the contributions of Contributing to Managing Epilepsy Well's Advisory Panel, a group of epilepsy experts and leaders in the field. We thank the panel for the direction and expertise it provided.

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