Barriers and facilitators to epilepsy self-management for patients with physical and psychological co-morbidity

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Abstract

Objectives: This exploratory study identifies barriers and facilitators to self-management to inform future epilepsy self-management interventions for persons who have epilepsy complicated by mental health conditions and serious medical events.

Methods: Focus group methods were used in a series of community advisory board meetings. Analysis was conducted using a thematic, constant comparative approach aiming to describe the range of barriers and facilitators salient to participants. There were total 22 participants, including 8 health professionals, 9 patients with epilepsy, and 5 care partners. Mean age was 49.1 (SD=11.0, range 32–69), 11 (50%) were female, and 11 (50%) were male. For those with epilepsy, mean years having epilepsy was 24.7 (SD=19.9, range 1–58 years).

Results: Individual psychological barriers (mental illness, fatigue, and psychological distress) prominently interfered with health behaviors. Community and family barriers included stigma, lack of epilepsy knowledge, and poor social support. Facilitators included planning for seizures, learning about medications, stress management, socializing with others, and talking with other epilepsy patients.

Discussion: Qualitative evidence in this study suggests a linkage between social integration and positive health behaviors. Future efforts to embed patients with epilepsy and their caregivers into clinical care processes could offset barriers and enhance facilitators.

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1. INTRODUCTION

Epilepsy is related to a substantially increased risk of injury and mortality, and the risk of death from any cause is three times higher in people with epilepsy compared to the general population.[1, 2] In addition to injury and death, seizures in epilepsy are often associated with psychological comorbidity.[3] While many persons with epilepsy live without complications, serious mental illnesses (SMI), such as psychotic illness, bipolar disorder and chronic depression, are disproportionately high (between 20% and 30%) in people with epilepsy and contribute to personal and health system burden.[4–9] Given the stigmatizing nature of both epilepsy and psychiatric illness, individuals with comorbid epilepsy and mental illness are doubly stigmatized. Social isolation and lack of support may predispose persons with epilepsy and mental illness to be less likely to receive the benefit of evidence-based therapies.[10] These individuals may avoid or minimize their use of preventative medical and neurological care, and instead using expensive, crisis-oriented, hospital-based care.[9]

As in prior intervention development studies by these investigators,[11] the theoretical model guiding the investigation is social cognitive theory.[12] According to social cognitive theory, individuals learn by observing others, and behave in specific ways to reach goals.[12] Individual knowledge, self-efficacy, and outcome expectancy facilitate the shift to healthy behaviors. More specifically, personal assessment of the ability to perform a behavior (self-efficacy) is a critical precursor to action and reaching a desired outcome.[12] Prior studies of self-management of epilepsy[13, 14] and mental illness[15, 16] have previously shown promising results when employing a social cognitive approach.

Optimal epilepsy self-management includes active involvement in treatment, use of evidence-based medication treatments, adoption of a healthy lifestyle to minimize seizure risk, and treatment of comorbid conditions.[17] Healthy self-management is likely to be exceptionally difficult for people with epilepsy and multiple additional risk factors, such as SMI, because they have to face challenges at so many levels. Medication non-adherence, poor understanding of the need for treatment routines, lack of belief in medication efficacy, side effects concerns, and practical barriers in getting prescriptions filled, picked up, or delivered are all known barriers to optimal epilepsy care.[18] Barriers to care and self-management also involve social exclusion, depressive or other psychiatric symptoms, on-going substance use/abuse as well as problems in regulation of sleep and wake cycles.[19]

Some epilepsy self-management experts note that the larger body of epilepsy research has focused too narrowly on clinical treatment trials and there is a need for research that examines the detailed perspectives and experiences of epilepsy patients.[20] Research comparing provider and patient perspectives on epilepsy self-management has found that clinician and patient concerns are often out of alignment, suggesting the need for involvement of patients in the design of interventions.[21, 22] Qualitative inquiry is an appropriate framework for learning how patients conceptualize their experience of disease

and qualitative research techniques have become an integral component to developing health promotion interventions in special populations.[23, 24] A better understanding of patient perspectives on illness and treatment can shed light on key mechanisms for promoting self-management. In this qualitative analysis conducted preparatory to the refinement and implementation of two epilepsy-focused studies, we identified and explored the range of factors that can impede or promote successful epilepsy self-management.

2. METHODS

This study was approved by the University Hospitals Case Medical Center Institutional Review Board (IRB). All participants provided written informed consent.

2.1 Study Design

We convened 6 community advisory board (CAB) meetings (two series of 3 meetings each), and used focus group methods to collect data from persons with epilepsy, their family members and other stakeholders. Sessions were focused on eliciting participant perspectives on barriers and facilitators to epilepsy self-management and on the development of an intervention to support self-management among vulnerable epilepsy patients and their care partners.

2.2 Sample and Setting

Inclusion criteria for patient participants were: able to provide informed consent in English, age 18 or older, had either (A) diagnosed with epilepsy and mental illness (DSM IV diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder or chronic/recurrent depression) or (B) diagnosed with epilepsy and had a history of at least three negative health events (hospitalization, emergency room use, or self-harm attempt) and receiving care at a publicly funded community healthcare entity. Participants were excluded if actively suicidal/homicidal, diagnosed with dementia, or pregnant. These eligibility criteria were confirmed by contacting each participant's health care provider, and mental illness diagnosis was further confirmed using a clinical diagnostic interview. All participants had experienced epileptic seizures, and participants had a variety of levels of current and past epilepsy severity and experiences, including primary generalized, tonic-clonic and partial seizures. Participants had also experienced a wide range of treatment modalities from medication therapy, to relaxation strategies, surgery, and vagus nerve stimulation.

Participants were recruited from urban medical center patient populations, local specialty care clinics, and community locations. In all, there were 22 people who participated in the two series of community advisory boards (CAB). Two individuals were in both series. The CABs consisted of 8 professionals working for local community health organizations, 9 patients diagnosed with epilepsy, and 5 care partners (1 partner, 3 spouses, 1 friend). Mean age of CAB participants was 49.1 (SD=11.0, range 32–69), 11 (50%) were female, and 11 (50%) were male. Seven CAB participants (31.8%) were white/Caucasian, 10 (45.5%) Black/African American, 1 (4.5%) American Indian, 1 (4.5%) Hispanic, and 3 (13.6%) chose other or refused to disclose. Ten (45.5%) attended 4 years of college or more, 8

(36.4%) attended at least some college, 3 (13.6%) completed high school, and one (4.5%) chose not to disclose.

The 9 participants with epilepsy were similarly diverse; , 5 (55.6%) were female and 4 (44.4%) were male, and 2 (22.2%) identified as Caucasian/White, 5 (55.6%) identified as Black/African American, one (11.1%) identified as American Indian, and one (11.1%) identified as Hispanic. Four (44.4%) were married/in a long-term relationship, 3 (33.3%) were single, and 2 (22.2%) were separated/divorced. Six (66.7%) attended 1–3 years of college, 2 (22.2%) attended 4 or more years of college, and 1 (11.1%) completed high school. Two (22.2%) patients were employed for wages, 4 (44.4%) were out of work/unable to work, 1 (11.1%) patient was retired, and 1 (11.1%) was a homemaker. Income levels were diverse with 4 (44.4%) making $25,000 or less in annual household income, 2 (22.2%) making $25,000-$50,000, and 1 (11.1%) making $50,000 or more. Mean years since being diagnosed with epilepsy was 24.7 (SD=19.9, range 1–58 years).

2.3   Qualitative Data Collection and Analysis

A moderator (MS) guided the focus group discussions, using a semi-structured interview guide. Participants were explicitly encouraged to express themselves openly, without concern for whether or not other participants agreed with their opinions. Data collection was stratified, such that the first cohort focused on persons with epilepsy and co-morbid mental illness while the second cohort focused on persons with epilepsy and history of negative health events. The interview guide elicited participant viewpoints on personal, family, and provider factors relevant to persons living with epilepsy and co-morbid physical and mental health conditions. At the outset of the first session, after introductions, participants were encouraged to tell a brief story relating to their life experience with epilepsy and describe the challenges they faced. Discussion was guided by the moderator, but the open format allowed all participants to direct the discussion toward a topic any participant deemed to be important.

The second session continued to list and articulate barriers and facilitators, with "round robin" style discussions in which participants had the opportunity to rebut one another's assertions and prioritize behavioral self-management strategies. For example, the discussion of self-management facilitators was prompted by asking participants to make a list and then share their responses to questions like, "What are some things that help you in taking care of your epilepsy?" while barriers were assessed by asking, "What things get in the way or prevent you from managing/taking care of your epilepsy?" These questions were purposefully broad, in order to promote a focus on topics important to participants rather than impose a particularly structure derived from the preconceptions of the study team. In both of the two meeting series, by the close of the third session it was clear that little new information was being provided, and the investigative team had consensus that further sessions would be unlikely to produce new insights.[25]

All group sessions were audio-recorded and transcribed verbatim. Debriefing sessions among study staff occurred immediately following each group session in order to record key insights and reactions in note form. Analysis of notes and transcripts was conducted using a thematic, constant comparative approach.[25, 26] We began with paper and pencil open coding

of printed transcripts and had a series of team meetings to discuss key themes and observations. Open coding was followed by axial and sequential coding in which the initial list of themes was reviewed, grouped and each theme compared with other themes for overlap.[27–30]

Once the initial coding dictionary was developed, subsequent coding was conducted using NVivo qualitative data analysis software (NVivo 10). Two members of the investigative team (AP, RR) reviewed each transcript to ensure that the application of the coding dictionary was consistent. All initial discrepancies were resolved at a series of team meetings. Significant statements and themes attached to the codes enabled robust characterization of perceived barriers and facilitators in the words of the participants.

Two methods, a member check and conversation analysis were used to validate the data and interpretations in this qualitative study.[29, 31] Analytic impressions from initial sessions were presented at subsequent sessions to the CAB participants where they had the opportunity to review, comment on, and extend the findings.[29, 32] Information was provided in outline form and participants agreed with the preliminary summary and conclusions, and added some clarifying statements.

To further understand data and discussion quality, we conducted a basic structural analysis of the conversations from the group sessions.[33] In this process we created three primary codes that could be used to describe the conversational context of each particular speech situation (conversation segment) in each session: (1) Responding to moderator/facilitator question; (2) Responding to another participant; and (3) Self-initiated speech. In analyzing group process data, it is important to examine communication dynamics in order to grasp whether the discussion focused exclusively on the interests of the moderator and facilitator, or whether group members were able to engage in a more meaningful discussion where they confirmed and disconfirmed perspectives of other participants. Coding of the communication structure was conducted by one team member (RR) and reviewed for accuracy by a second team member (AP). Of the 1223 unique segments of text attributed to CAB participants, 505 (41%) were stated in response to the moderator or facilitator, 401 (33%) were stated in response to other participants and 317 (26%) were initiated and shared by participants as new directions for the discussion. This distribution of the conversation suggests a balance between discussion guided by the moderator and facilitator and emergent discussion derived from the interests and goals of the participants.

3. RESULTS

The barriers and facilitators to self-management were classified into an ecological taxonomy at three levels: individual, family and community, and health care services. This structure for presentation of the results is consistent with the principle of "reciprocal determinism" in social cognitive theory, in which a set of feedback loops exist whereby individual, group and environmental factors influence each other in determining health behavior outcomes.[34]

3.1 Barriers to Self-Management

Psychological barriers were among the most prominent of the individual-level barriers described (Table 1). These included the myriad ways in which mental illness can interfere with epilepsy self-management, as well as fatigue, frustration and psychological distress. Cognitive impairment and functional disability were also cited as important challenges to self-management. One of the participants described how cognitive impairment makes it difficult to communicate with health care providers:

> "Like I would be talking to you and I would be looking dead at you and I would, you'd be talking about one thing and I'm looking dead at you, but a couple seconds later you know, I would miss part of the sentence. I'm saying I'm here but the conversation is here [motions elsewhere]. That little seconds, so I missed it."

Epilepsy knowledge was discussed in direct relation to psychological and cognitive barriers. Participants stated they had a hard time grasping the constantly-evolving terminology that doctors used to describe their disease situation, and that this left them feeling frustrated and experimented upon. For example, a participant stated:

> "I was told when I was diagnosed that it was a high fever as a baby, there was scar tissue in the brain. But up here I was told that no one could have known that in the 70s because they didn't have enough expertise to know something like that."

Community and family-level barriers to self-management included stigma, lack of knowledge about epilepsy, poor transportation and a lack of social support (Table 2). Notable among the community and family level barriers was a tendency for barriers like stigma and transportation to reinforce and perpetuate other barriers. For example, a person who doesn't want to tell others that they have epilepsy is likely to become more socially isolated. Similarly, transportation difficulties can amplify problems of health care access, and lead to a cascade of frustration, isolation and psychological distress, which participants perceive as triggering seizures.

For example, several participants agreed that the inability to drive amplifies social isolation by creating an additional barrier to developing and maintaining friendships and intimate relationships, P2: *"Yeah. I can't even go pick a woman up and go on a date!"*

Barriers to health care services (Table 3) were identified as having a salient influence on participants' ability to self-manage. These barriers pointed at an overall lack of patient-centeredness experienced by those with epilepsy co-morbid physical and mental illnesses in their interactions with the health care system. Participants also highlighted a cascade of challenges associated with the long term side effects of their epilepsy medications (e.g. osteoporosis and tooth decay caused by anti-seizure medicines) and the need for providers to be holistic in helping patients to manage a wide array of challenges.

3.2 Facilitators to Self-Management

Study participants also identified multiple epilepsy self-management facilitators. Tables 4, 5 and 6 present the identified facilitators at the individual, community, and health service levels. The participants were keenly aware of the strategies that they had found helpful. The

range of health facilitating factors fits into the personal explanatory models that the patients had for their health, and are therefore useful potential targets for programs and interventions seeking to improve outcomes. For example, participant 4 emphasized the value of stress reduction in preventing seizures:

> "…different things ya can do to reduce the stress, which in turn help, help you stay away from havin' a seizure."

At a subsequent CAB meeting, he brought printed copies of a publication titled "100 Ways to Reduce Stress" to share and discuss with the group as a potential component of future epilepsy interventions.[35]

Participants described effective strategies for epilepsy management, such as seizure prevention and learning about epilepsy medicines, as well as mental health facilitators concentrated around stress reduction and social support. While the participants discussed a number of mental and psychological self-care barriers, they identified relatively few facilitators that they directly linked to better mental health. However, many facilitators are likely to promote better outcomes for both epilepsy and mental illness. For example, a regular sleep schedule, positive social activities and a holistic integrated approach from care providers are likely to have epilepsy and mental health benefits. Facilitators with joint benefits might be potentially important components of future interventions.

4. DISCUSSION

This study identified barriers and facilitators of epilepsy self-management in individuals with mental health comorbidity and in those with recent medical events, who might also be expected to be at greater risk for psychological complications. Such individuals are traditionally hard to reach and often excluded from clinical trials. Building on previous work in chronic disease self-management[11, 36] research and clinical care in epilepsy,[37, 38] and work with underserved groups in community settings,[39] we utilized an iterative, collaborative process to solicit feedback from a diverse group of people with epilepsy and other stakeholders. The ecological structure of participant responses was consistent with the basic tenets of social cognitive theory. As described by Viswanath (p. 168), "individuals and their environments interact and influence each other—reciprocal determinism—resulting in individual and social change."[40] Active self-management is critical in minimizing the morbidity and mortality associated with epilepsy. People who have epilepsy complicated by comorbidity are challenged to adhere to care plans which may be complex, involving multiple types and classes of medications, multiple care providers, and health care settings that are distinct and/or not coordinated.

Other researchers have recognized the complexity of promoting self-management among patients with epilepsy, and that self-management is tightly linked with epilepsy health outcomes.[41, 42] A recent landmark qualitative study by Hartley and colleagues systematically reviewed and collated results of qualitative work on the barriers and facilitators among persons with a wide range of brain disorders, including epilepsy.[19] Our work confirms and extends these prior findings that patient knowledge and care provider indifference are important barriers, and that social inclusion is a valuable facilitator for

persons with epilepsy.[19] Our results are also an important extension of prior work, in that there is little qualitative work on epilepsy relative to the other brain disorders in the review (i.e. depression, multiple sclerosis, Parkinson's) and that our work is the first to specifically examine barriers and facilitators among persons whose epilepsy is complicated by other physical and psychiatric morbidity.

Considerable prior qualitative research has examined quality of life and illness experience among persons with epilepsy.[19] Kerr et al. synthesized across age groups to develop a conceptual model characterizing the epilepsy experience.[43] Our study extends this prior work by examining the specific barriers and facilitators to self-management among a particularly disadvantaged group. Among the more notable findings that differ from prior work are the identified health care system barriers (Table 3). Although these barriers might be attributed to differences in sampling from small, local qualitative samples, future research investigating how persons with epilepsy and mental illness experience care processes is warranted. In addition, analysis of the qualitative data in this study identified a fairly comprehensive set of potential facilitators for improving care and self-management (Tables 4–6). For example, while prior studies have identified the contours of stigma for persons with epilepsy,[44] our study participants also described the potential for communication strategies, public outreach and contact interventions to reduce stigma (Table 6).

Our study has important limitations. The most serious limitation of this study is the small sample size from a single community. Further investigations in different samples might detect additional epilepsy self-management barriers and facilitators, and further work is necessary to establish the extent to which these barriers and facilitators are endorsed by larger numbers of patients. While our study had participants from multiple racial and ethnic backgrounds, lay understandings of illness can have culturally specific components and future work will be needed to understand how self-management barriers and facilitators vary across groups. Another limitation is that we used a single mode of qualitative inquiry, group discussion. Participants in one-on-one interviews or data collected from direct observations might yield other insights not reported in the group format. Despite these limitations, our conclusions are buttressed by the use of rigorous qualitative data collection and analysis techniques, and by their correspondence with the findings of prior empirical and theoretical work.

Persons with epilepsy that is complicated by mental health conditions, co-morbidity and serious medical events identified a number of important barriers to self-management. Key barriers were a set of themes characterized by a lack of patient-centeredness and a poor experience of care for persons with epilepsy. Consistent with prior qualitative work we found that the presence or absence of supportive others (or the lack thereof) was a pivotal factor.[10] Social cognitive theory posits the importance of supportive social relationships among persons with chronic illness. In a direct confirmation of the principle of reciprocal determinism, our participants observed that their illness actively interfered with their ability to build and maintain supportive relationships, which in turn made it difficult to engage in heathy behaviors.

In addition, self-efficacy and treatment outcome expectations can alter the likelihood that individuals will engage in health promoting behaviors.[12, 41] Thus, we can expect that persons with epilepsy who face their medical care with mistrust and frustration, who experience the double stigma of co-occurring disorders, low social support, and become socially isolated, will be less likely to engage in positive self-management routines that promote physical and social well-being.

Nevertheless, stakeholders in our study reported a number of strategies to combat social isolation and promote well-being. Persons with epilepsy who are supported and integrated into regular social activities may be more likely to follow through with health behavior recommendations, leading to better outcomes. Future efforts to involve patients in treatment decision-making and embed patients with epilepsy and their caregivers into clinical care processes could offset barriers and enhance facilitators identified in this qualitative study.

Acknowledgments:

Abbreviations:

AED	anti-epileptic drug
IRB	Institutional Review Board
ESM	epilepsy self-management
Epilepsy	epilepsy and mental illness
CAB	community advisory board
SD	standard deviation
SUDEP	sudden unexplained death in epilepsy
SMI	serious mental illness

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Table 1.

Person-Level Barriers to Epilepsy Self-management

Themes and Categories	Illustrative Quotes from Participants (N=22)
Psychological Barriers	
Challenges of having Epilepsy and a mental disorder	*"..I couldn't even contemplate what it would be like only having epilepsy because I have both. ..I would probably enjoy how much easier it would be to have A without having B."* – Participant 4
Stress	*"..stress can bring on a lot of different things. High blood pressure and the works, you know, and the next thing ya know you're a walkin' time bomb."* – Participant 4 *"Like after I leave her today I will probably have seizures because all of this is very stressful to talk about."* – Participant 3
Frustration with Doctors	*"Yes. The care providers don't listen, it's just like this."* – Care Partner 1
Medication cost/availability	*"Well what about this medication? Oh this medication is so expensive you are going to have to order it from Canada because it's $700."* – Participant 1
Medication side effects	*"I've been on many medications. They've caused vomiting, they've caused bad rashes. They've caused all kinds of different. They've caused stumbling, they've caused you know where I've felt like I, like suicidal type things, and I stopped them immediately. They've caused um frustration, not being able to sleep ugh."* – Participant 3
Reluctance to take medication	*Some don't want it, some don't wanna take it, they think, oh I don't need this… and they just wouldn't take it, and then of course they'…end up in the hospital…* Participant 12
Seizure unpredictability	*"I'm on the bus coming from the grocery store, feel one coming on, pulled the cord, I'm in the hospital"* – Participant 1
Tired of constantly managing illness	*"It's not the fact that you don't want to take your pills. It's the fact that you're just so tired of seeing, of hearing that alarm. You're tired of seeing that note."* – Participant 1
Functional Impairment and Illness Barriers	
Burden of adjusting to life with Epilepsy	*"..I want to be independent. I don't want to live with my momma."* – Participant 2 *"Now they started happening at work a lot. That's why I had to… finally stop. I was doing landscaping at a golf course in Florida and I was on a golf cart riding from the building, the clubhouse, and cross the road over to maintenance. Don't even remember how I got there."* – Participant 3
Cognitive impairment interfering with self-management	*"..remembering to take my meds. Since I had the surgery… my memory is just getting worse and worse, and then with the meds and everything."* – Participant 4
Communication difficulties caused by epilepsy	*"…in my mind I can hear what I'm saying, but when I try to say it, it comes out like a foreign language."* – Participant 3
Managing multiple illnesses	*"..I have a hard time finding a cold and flu medication, because it can provoke a seizure."* Participant 14
Knowledge Barriers	
Insufficient knowledge of diagnosis and treatment	*"..I thought I had an anxiety condition, and was mentally ill."* – Participant 3 *"..It seems like it's always experimental what they're trying to do."* – Participant 3

Table 2.

Community Level Barriers to Epilepsy Self-management

Themes and Categories	Illustrative Quotes from Participants (N=22)
Societal Barriers	
Stigma	*"Some of my clients see the epilepsy and say well everybody is going to think this or they're going to think that, they are going to think negative about me."* – Community Member 3
	"I grew up with it and I was tortured many times as a kid…" – Participant 4
	"They're doubly stigmatized…the condition itself has stigma, but also any other mental health issues themselves also have, so it's like a double stigma thing." Community Member 8
Disclosure	*"Well I think other people, um not knowing how they would react if they knew. So, I don't really, like, talk about it to anybody… I don't tell anybody I have epilepsy…"* – Participant 3
Exclusion	*"For job purposes, I think more employers are more paranoid with someone with a seizure disorder than someone without one"* – Participant 1
Lack of Public Knowledge	
Seizure risks	*"If kids are playing video games when he comes over you must stop playing all games, you must sit down, cut the TV off, cut the lights off."* – Comm. Member 3
What to do	*"Before I even knew what a seizure was I was younger and they said a person that swallows they tongue you stick a spoon in they mouth."* – Care Partner 2
Misinformation	*"..people tell me when they went to church and they had a seizure that people started putting oil on them. We gonna cast the demon out of you."* – Community Member 3
Transportation	*"So my license is taken away, hey you can only work certain jobs now."* – Participant 1 *"… if you're takin' a bus, you know, you can't get there…"* – Participant 3
Support Barriers	
Lack of support	*"I mean I'm by myself so you know."* – Participant 2 *"…a lot of my clients tend to burn bridges with families, so family as a support is sometimes not there."* – Community Member 3
Lack of relatable resources	*"I was a part of …this epilepsy support group, and their cases were worse than mine, and it made me feel like, I didn't belong there…"* – Participant 1 *"…it's like you're surround by family and everythin'. And they know everything, but they don't know nothin'."* – Participant 2

Table 3.

Health Service Barriers to Epilepsy Self-management

Themes and Categories	Illustrative Quotes from Participants (N=22)
Health Care Provider Barriers	
Mistrust of providers	*"the nurses understood, but the doctor he just wanted that new medication, and take it, an'…was usin' me as a, I was with all of these electrodes, I didn't have any choice. That's not good."* – Participant 3 *"..and then when I had issues with my surgery. And trying to get answers. That was a big problem, because he's supposed to be one of the best in the world from what he told me."* – Participant 2
Poor Communication	*"Or he's just interested in a, a procedure that he wants done, like with me, what they did with drawing the medicine and puttin' me on another medicine without even telling me."* – Participant 3 *"The care providers don't listen, it's just like this."* – Care Partner 2
Not patient-centered	*"There's me, there's doctors, and there's society. Okay. It's like okay I'm an individual. I'm not a statistic, okay. …I'm not an epileptic number 70465 of doctor Mario and Luigi, you know what I mean."* – Participant 1 *"..they're prescribing all these medications to the patients, but they never do any tests for like their liver. I mean these pills, this medication is, from what I read in the last 12 years, is very hard on the liver."* – Care Partner 2
Access Barriers	
Lack of access to	
Providers	*"…being able to get in touch with my doctor can be a big problem. You know, especially when I, you know when you desperately need to."* – Participant 2
Medicine	*".. I had to argue with the drug store and like with my tegretol the way they got around it I guess in my mind because Walgreens and CVS all of them they just stopped carrying tegretol. I mean they stopped carrying it."* – Participant 3
Transportation to appointments	*"…not being able to drive, it seems like public transportation isn't available and/or not covered by any insurance, just because you're able to walk, but you're not able to drive."* Care Partner 3
Lab results	*"I have to go and get them at the hospital, you know, ask someone else to look it up in the computer or go to medical records and ask for the record to ask what it is myself…"* – Participant 3
Disability policy	*"..you can't work every job anymore, but you can still do some things so you're not disabled enough. So you don't get SSI or disability. Okay, so now I go to work. Oh you had a seizure on the job, you're fired."* – Participant 1
Treatment Barriers	
Testing and Procedures Too frequent Too invasive Not beneficial	*"…but what they said what it would do is the electricity will go to the, whatever is on my spine and eat it, so it wouldn't go through my brain and have a seizure. They're like well the risks are paralysis. You ain't paralyzing me."* – Participant 4 *"They have no idea where you got epilepsy from. So you say EEGs, EKGs, LMNOPs, XYZs, CatScans, Dog Scans, sleep deprivation tests, try this medication, try that medication and what are you still having? Say it with me now, Seizures."* – Participant 1
Frequent medication changes	*"…tried this medication, that medication and finally this what I'm taking and take this one, and take that one away and this one is over here, well switch this one around, and we'll take this one away also."* – Participant 4

Table 4.

Person-Level Facilitators to Epilepsy Self-management

Themes and Categories	Illustrative Quotes from Participants (N=22)
Seizure Planning	
Aura warnings	*".. if you're lucky enough to have an aura, 'lotta times you can more or less sit yourself down and make sure that you're not around any uh hard objects…"* – Participant 4
Planning how to communicate with others	*"What my friends and I do, we have um, we have an inside joke so that they, they'll ask me the question, you know, and I will, and you have to be conscious to be able to answer the question, so if I'm conscious and I hear them ask a question, I know they're askin' me do you know you just had a seizure, as opposed to they ask me the question, I give a answer, they know I'm not there because they know I'm not laughin' at the joke…"* – Participant 1
Medical ID	*"I was I was at a play, you know, and I stood up…and I felt a seizure come on. I literally grabbed…ran up to some guy, grabbed his arm, pulled out my epilepsy tag, and then that's all I remember."* – Participant 1
Education	
Learn about medications	*"I have a thing called the pill book and you need to look up and see uh, what those medications do…"* – Participant 3
Learn about epilepsy	*"Learning about epilepsy and about mental illness, so education can be important."* – Facilitator *"That's number one."* – Participant 4
Understand triggers	*"Whatever you're doing that's working continue to do, and that way the epilepsy seems to be under control. Address the mental health."* – Community Member 3
Social	
Socializing	*"Actually people who have a problem, but don't know I do, talking to them about their problems make me feel, you know, a little more important like I'm helping them out, and that happens a lot when you're riding the bus… There's all kinds of people on the bus."* – Participant 3
Help others	*"When I get out and I'm doin' things, like helpin' people and stuff like that, that just takes me off, and takes my mind away from everything."* – Participant 2
Engage in positive activities	*"Like we go to basketball games, we go to um we go to the mall and um we go thrifting. At that point her seizures aren't as numerous…"* – Care Partner 1
Self-Care	
Sleep	*"…have some routine…like goin' to bed at the same time…"* – Participant 3
Exercise/physical activity	*"…we get our exercise in, even if it's walking through our mall. Well, P9's in a wheelchair, so using his arms and legs [in the wheelchair], we consider that exercise for him, 'cause he'll [wheel] the whole length of the mall and um, even if we go to a store, we're not buying anything, at least we walk around the store and we look at things"* – Care Partner 5
Minimize stress	*"Doing things for other people… I love animals. Animals are definitely a stress reliever. I have a pet cat, all of that is a stress reliever."* – Participant 3
Memory aids	*"I have alarms and notes, post-its all over."* – Participant 2
Self-acceptance	*"I was diagnosed in 2003…and I just now come to terms with the fact…you know…that I have epilepsy. I mean, I've fought it this whole time."* – Participant 1
Avoid Substance Use	*"Yeah, no drinking. No drugs, uh, recreational drugs."* Participant 12
Coping Mechanisms	
Spirituality	*"And they said well how do you cope with it. Well when you're faced with a situation like that you just say Lord, you know, give me strength. I was always taught you know you just say Lord give me strength to deal with whatever and so I learned."* – Care Partner 2

Table 5.

Family and Community Level Facilitators to Epilepsy Self-management

Themes and Categories	Illustrative Quotes from Participants (N=22)
Social Support	
Emotional support	*"And um I told him when we first started talking that it doesn't bother me what your condition is, I will be here every day of your life. Be here for you no matter what, we will get through this together."* – Care Partner 2
Instrumental support	*"And it's like yeah, my, my significant other, my lady she's like you know did you take the pills, take the pills, take the pills, you know what I'm saying. I'm glad she asks, I'm glad she reminds me you know what I mean."* – Participant 1
Talk to others with epilepsy	*"…a lot of people don't understand it, but a person who has epilepsy definitely does, so you have a person with epilepsy talk to the person that isn't sure, and that would definitely get 'em on the right path…"* – Care Partner 2 *"..it would be nice to hear what other people have to say, instead of you know just talking to people online."* – Participant 2
Public Knowledge	
About seizures & What to do	*"information that needs to go to the general public about this illness so people know more, and that can be a, you know, public policy that will begin to start stressing that we need to educate people."* – Community Member 2
	"I've actually witnessed a seizure twice in my life and I think I agree with all of the individuals that have epilepsy that it's really uh helpful to know one, that this person actually has a seizure disorder, and two, how to manage an aura" – Community Member 5
About legal rights & accommodations	*"So, a lot of times, you know, school districts won't take a 504 as seriously as they do an individualized educational plan [IEP]. So, just making sure that, you know, when he moved from one grade to another, um, that the -the 504 followed him. And that his teachers when he moved on, knew about his condition and knew about the accommodations that, legally, he could have in the classroom."*
Community Resources	
Support groups	*"I agree with you and so.. it's gettin' me to think about some things, of how maybe we could kinda create a better support network, or a stronger support network, maybe that's what it should be. And even, you know, spaces and organizations that maybe um, they could be some self-help groups that could meet."* – Community Member 2
Recreation centers	*"So you need to have somethin' that you're for sure of, community agencies, whether it's a senior center, whether it's a recreation center, something in that area that's available to you…., it'll give ya a chance to be active around other people, just a change of atmosphere."* – Community Member 3

Table 6.

Health Service Facilitators of Epilepsy Self-management

Themes and Categories	Illustrative Quotes from Participants (N=22)
Provider Support	
More frequent appointments	*"I would say having appointments with your neurologist more often."* Participant 1
Holistic approach	*"…so our case managers are actually gonna be trained in a lot of the medical underlying problems, like epilepsy, diabetes, and heart disease, those kinds of things. Which will allow us to have a holistic approach to the care of the clients we serve."* – Community Member 1
Provider Knowledge	
Educating all healthcare providers about epilepsy	*"I would bet that most of our treating clinicians that work in the community mental health centers, ….probably don't know how to respond necessarily when somebody's having a seizure. And so having that educational piece would be really helpful."* – Community Member 5
Discussions with medical students and staff	*"..we talked, or to say I talked and they listened…"* – Participant 4
More epilepsy research	*"Do more research I guess on finding medications… it just doesn't seem like there's that many that they have come up with. It's almost like they've just put that aside and then concentrate mainly on the cancers and a lot of other things."* – Participant 3
Alternative Methods/Medicines	
Prescription mail order	*So I now get it from a drugstore that mails it to me"* – Participant 3
Health fairs	*"We just had a health fair…and they do different things with you…to try to keep you motivated…"* – Care Partner 2
Medical marijuana	*"..They sayin about the medical marijuana. They said that's good for the people."* Participant 10