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ENGAGING STAKEHOLDERS IN THE REFINEMENT OF AN EVIDENCE-BASED REMOTELY- DELIVERED EPILEPSY SELF-MANAGEMENT PROGRAM FOR RURAL POPULATIONS

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Abstract

A growing body of research supports self-management approaches that can improve outcomes in people living with epilepsy (PLWE). An evidence-based remotely-delivered self-management program (SMART) that was successfully delivered in an urban/suburban setting, has the potential to be particularly helpful to PLWE who live in rural communities, where heavy stigma burden and limited access to healthcare is common. In this Phase 1 exploratory study, focus groups of key rural stakeholders (PLWE, family members, care providers) were used to: 1) gather information on factors that may impede or facilitate participation in SMART, and 2) elicit overall perceptions of the program, as well as suggestions and feedback for refining it for implementation in Phase 2 of the randomized controlled study (RCT). Qualitative data analysis revealed that focus group participants identified geographic and social isolation, and the more limited access to epilepsy care, as the major barriers to epilepsy self-management for rural populations. However, they felt strongly that SMART could fill an epilepsy care gap in rural communities, and provided suggestions for recruitment and retention strategies of subjects, as well as improvement/modifications to the program curriculum for the Phase 2 RCT.

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Keywords

Qualitative research; Epilepsy self-management; Key stakeholders; Rural and under-served populations

1. Introduction

Epilepsy is associated with extensive burdens including frequent medical complications, high levels of comorbidity, poor quality of life, and premature mortality [1–4]. Risk factors for poorly controlled epilepsy include limited social support, poor medication adherence, and comorbidities like mental illnesses and substance use [4,5]. Lifetime prevalence of epilepsy in the U.S. is estimated to be 1.2 to 2.9% [6–9]. Importantly, the number of Americans with active epilepsy may be increasing as suggested by a national survey which found a significant growth in the number of epilepsy cases between 2010 and 2015 [10–13]. In spite of advances in biological therapies, many people living with epilepsy (PLWE) have poor outcomes including negative health events (NHEs) such as frequent seizures, accidents and emergency department (ED) visits, and low quality of life [1–4].

A growing body of research supports self-management approaches that can improve outcomes in PLWE [14], and The Managing Epilepsy Well (MEW) Network has been a national leader in developing, testing and disseminating evidence-based epilepsy self-management programs [15]. One of these programs, **Self-management for PLWE and a history of negative health events (SMART)** developed by researchers at Case Western Reserve University (CWRU), is an on-line 8-week interactive group-format epilepsy self-management program that targets those who have had recent epilepsy-related complications. SMART was delivered via the internet on personal computer tablets, using posters/graphics, and emphasizing interactive discussion. SMART stresses information-sharing in a way that is accessible to participants and fosters motivation for active self-management. The SMART sessions are operationalized in written curricula, including an interventionist's manual, participant's manual, slides and handouts, role playing, and are collaboratively delivered by a Nurse Educator and a Peer Educator. Telephone call-in was available for those with limited Internet access. SMART emphasizes management of lifestyle and emotions/mood, treatments for epilepsy, seizure control, relationship between epilepsy and stress, as well as strategies to cope with stigma. Curriculum topics addressed in the 8 week sessions are presented in Figure 1.

Following the 8 group sessions, participants had six telephone maintenance sessions (spaced approximately 2 weeks apart), with the Nurse Educator and Peer Educator alternating calls. Participants were asked how they were doing with attempting to meet their personal care plan (established during the SMART group sessions) and educators reinforced messages from SMART that might help them meet their goals.

In a 6-month randomized controlled trial (RCT), SMART (n=60) was associated with a reduction of epilepsy-related complications, improved quality of life, and physical and mental health functioning compared to wait-list (WL) controls (n=60) [16]. Longer-term outcomes with SMART also look promising. A 12-month post-RCT extension suggested

that PLWE who participate in SMART sustain health outcomes at 1-year follow-up, and may have additional incremental improvement in seizure frequency and mood [17].

This remotely-delivered group-format approach used to deliver the self-management curriculum, has the potential to be particularly helpful to PLWE who live in rural communities where heavy stigma burden and limited access to healthcare is common. PLWE in rural/semi-rural communities also face challenges such as social isolation and low levels of epilepsy awareness, both of which impede help-seeking and exacerbate epilepsy stigma [2–7]. There is also evidence of worsening of some rural-urban health disparities. Many rural residents experience behavioral risk factors and poor overall health status. They have higher rates of obesity, sedentary behaviors, poorer diets, and greater tobacco use than urban residents. Rates of premature mortality and health conditions, such as obesity and heart disease, are also higher, and rural individuals, who are also often financially disadvantaged, may experience challenges to epilepsy care and evidence based interventions [18–21].

While results of the first RCT conducted to date on SMART suggest that it could be an important part of epilepsy care for PLWE, the single site-setting in an urban-suburban population in Northeast Ohio limits interpretation of how it might impact more diverse groups with epilepsy. In order to refine SMART for a rural/semi-rural population, we elicited input from key stakeholders, PLWE and their caregivers living in these communities in Iowa and Ohio, and urban/suburban health care professionals who provided care to PLWE. The aims of this Phase 1 exploratory study were to: 1) gather information on factors that may impede or facilitate participation in a remotely-delivered epilepsy self-management program among people who live in rural settings, and (2), elicit their overall perceptions of SMART, as well as their suggestions and feedback for refining it, for implementation in Phase 2 of the randomized controlled study (RCT).

2. Methods

2.1 Study design

In this cross-sectional exploratory study, we used a community-based participatory research (CBPR) approach, with its emphasis on partnering with communities, to gather information needed to develop a deeper understanding of the issues surrounding the refinement and implementation of the SMART self-management program for PLWE in rural Iowa and Ohio. The strengths of using this approach are that it allows for the innovative adaptation of existing resources, explores local knowledge and perceptions, and empowers people by considering them agents who can investigate their own situations [22].

2.2. Sample and Setting

A convenience sample of focus group participants was recruited via clinician referrals from both the Department of Neurology, at the University of Iowa Hospitals and Clinics, the Neurological Institute at University Hospital Cleveland Medical Campus, and Epilepsy Foundations and Epilepsy Associations in both states. In order to enhance the credibility and validity of our study findings, we solicited input from multiple types of key stakeholders involved with epilepsy and its care and treatment of PLWE living in rural/semi-rural areas

[23]. Our aim was to enroll a good representation of rural /semi-rural PLWE and family members, as well as providers who had experience in working/interacting with these PLWE. Residence status of PLWE and family members was assessed using the 2013 Rural and Urban Continuum Codes (RUCC) based on home zip-code [24].

Potential informants were initially contacted by research staff in an email message describing the project. If email addresses were not available, telephone contact was made. If initial contact yielded no response, two further messages and a final phone call were employed. Of the 27 PLWE that were contacted, 13 (48%) accepted the invitation to participate of which 6 (46%) were female and 7 (54%) were male. Of the 14 PLWE who declined, 5 (36%) were female and 9 (64%) were male. As for the family members, out of the 17 that were contacted, 5 (29%) accepted the invitation to participate, of which 4 (80%) were female and 1 (20%) was male. Of the 12 family members who declined, 9 (75%) were female and 3 (25%) were male. Of the 18 healthcare providers that were contacted, 15 (83%) agreed to participate of which 12 (80%) were female and 3 (20%) were male. Of the 3 healthcare providers that declined, 1 (33%) was female and 2 (67%) were male.

The final study sample of stakeholders consisted of 13 PLWE, 5 family members, and 16 care providers such as clinicians, administrators, and other professionals who interact with, or provide care for rural or semi-rural individuals. For qualitative research, this sample size of 34 participants is well within the recommended number of 20–50 individuals for theoretical saturation [25]. All participants signed an informed consent form, and were compensated for their time. The study was approved by the local institutional review boards (IRBs).

2.3. Qualitative data collection and analysis

Qualitative research has become an integral component to developing health promotion practices in special populations [26]. Focus group methodology was used to collect narrative data from key stakeholders in rural communities in both Iowa and Ohio. This data collection method allows interviewees to express their opinions and ideas in their own words, and they are an appropriate strategy for learning the vocabulary and discovering the thinking patterns of the target audience, as well as for discovering unanticipated findings and exploring hidden meanings [27]. Four focus groups were conducted via Zoom video conferencing on personal computers, phone, and tablets and consisted of two separate focus groups of PLWE and their family members (N=18) and two separate focus groups of care providers (N=16).

The groups, conducted by a skilled and experienced moderator (MS), were 60-minutes in length, and continued until little or new information was generated, or theoretical saturation had occurred [28]. Views on perceived barriers and facilitators to self-management of epilepsy among people living in rural or semi-rural settings, as well as impressions of the self-management curriculum, were elicited from the focus group participants. A semi-structured interview guide, adapted from previous studies in self-management of neurological conditions by the CWRU investigators [29, 30], was used to focus the discussion on these main topics and specific topic-related questions. For example, under the topic, “barriers to managing epilepsy,” the following question was asked of the PLWE *“What kind of things might get in the way, or prevent you from managing/taking care of*

your epilepsy?” For the family members, the same question was asked, but from their perspective: *“What kind of things might get in the way or prevent your relative from managing/taking care of his/her epilepsy?”* Additionally, the care providers were asked to respond to these same questions regarding the PLWE to whom they provided services. This same procedure was used to query the focus group participants on the topic, “facilitators to managing epilepsy,” by asking the question *“What things help in managing/taking care of your epilepsy?”* The focus group guide also included examples of follow-up probes such as *“would you explain further,” “please describe what you mean,”* and *“would you give me an example.”*

Focus group participants then viewed a slide presentation on the history and outcomes of the SMART program, as well as components of the self-management curriculum. An interactive discussion of their impressions of the program, as well as suggestions for refinement and modifications of the program, then followed. At regular intervals during the focus groups, the moderator focused on confirming and verifying with participants what was said and discussed (member checking) [25]. In addition, two members of the research team (CB, KCZ) took comprehensive notes describing first impressions and summarizing key findings. All interviews and focus groups were audiotaped and transcribed verbatim, and all personal identifiers were removed from the final transcripts.

Transcript-based analysis was used to analyze all textual data. In this method, the researcher uses the transcript itself as the source of textual data to be analyzed [23]. We used a grounded theory approach to data analysis, encompassing open, axial and sequential coding, and the constant comparative method to generate constructs (themes) and elaborate the relationship among them [28]. To ensure consistency and transparency of the coding, focus groups transcripts were coded and analyzed separately by two investigators (CB, MS); discrepancies were resolved by discussion. A separate coding dictionary that included mutually exclusive code definitions, was then constructed for the focus groups. The coding structure for each was reviewed after a preliminary analysis of a sub-sample of transcripts, and each dictionary was refined through comparison, categorization and discussion of each code’s properties and dimensions [28].

3. Results

3.1 Characteristics of the Sample (Table 1)

PLWEs (n=13) were white, mostly married, college educated males and females, with a mean age of 48.5 (SD=11.5). The age diagnosed with epilepsy ranged from 1–47 years (M=15.88;SD=14.68). While eight (61%) were retired or employed, five (38%) were out of work, or unable to work. Seven (53%) reported an annual income of \$25,000 or more, and six (46%) reported less than \$25,000. Health insurance coverage was represented by a combination of private, Medicare, and Medicaid. PLWE’s reported an average of 57.55 (SD=41.85) travel miles to visit their epilepsy provider whom they visited on an average of twice a year. Family caregivers (n=5) had a mean age of 59.4 (SD=9.55), were predominately white, married, college educated, females, who were either a spouse or parent of a PLWE. Three (60%) were retired, two (40%) were employed, and the mean number of years caring for a family member with epilepsy was 28 years (SD=21.9) The majority had

private insurance, as well as Medicare, and reported an annual income of \$50,000 or more. On the RUCC continuum for our sample of PLWE and family members (N=18), there were no individuals who currently lived in high density urban/suburban settings (category 1), there were 9 (50%) of individuals who lived in lower density urban/suburban settings (categories 2 & 3) and 9 (50%) who lived in semi-rural/rural settings (categories 4–9). There were no gross qualitative differences between the group with RUUC2/3 and RUUC 4 or higher.

Care providers (n=16) were also predominately white females with a mean age of 48.3 (SD=14.1). Their professional roles were varied, and included primary care clinicians, neurologists, epileptologists, as well as social workers, pharmacists, advanced practice nurses, and others listed in Table 1. Years of providing services to PLWE ranged from 1–35 years (M=15; SD=11.9)

Transcript-based analyses generated major issues or themes associated with barriers and facilitators to epilepsy self-management, as well as the discussion and comments about SMART. These “themes,” as well as the descriptive content categories contained within them, are summarized in their corresponding tables (tables 2, 3 & 4) and described in the following narrative. Representative quotes, randomly selected from each focus group, were used to demonstrate the transferability of the majority of the findings.

3.2. Barriers to Self-Management of Epilepsy (Table 2)

The six overarching themes that arose from the focus group discussions about barriers to self-management of epilepsy were: 1) Psychological issues, 2) Biological issues, 3) Medication issues, 4) Financial issues, 5) Access to Care issues, and 6) Epilepsy and Health Knowledge issues.

3.2.1 Psychological Issues—All stakeholder participant groups cited stress, related to lifestyle factors such as work, school, and family issues, as the most prominent of the psychological barriers to epilepsy self-management, and regarded it as a major seizure-triggering factor:

“So we know there are many different factors that contribute to epilepsy seizures but stress is probably at the top of the list.” Provider #9

“Stress is probably my number one cause of seizures, absolutely by far! Right now, I’m furloughed from my job and I have kids and family. My stress has probably gone up!” PLWE #10

“I was just going to say that stress is a major factor. I have more seizures when I am majorly stressed then I do when I just have mild stress.” PLWE #2

Second to stress, all focus stakeholder groups identified the prevalent stigma and cultural attitudes towards epilepsy significant psychological barrier to self-management. One PLWE who had epilepsy and recurrent seizures for 60 years talked about the stigma and embarrassment he still felt about his condition:

“I’ve had seizures for a long time, over 60 years and I’m still embarrassed, I don’t tell people I have seizures. PLWE #12

Care providers felt that stigma and cultural attitudes about epilepsy were endemic in rural communities, and the reason that many PLWE did not want to disclose their condition:

“There’s an incredible stigma in rural communities where our veterans are coming from. People here tend to be less familiar with epilepsy so our veterans don’t want to disclose their condition with their families or at work, because driving is a huge issue and they could have their license revoked.” Provider #14

“I’m probably in a unique situation in the free medical clinic because probably about 90% of our patients right now English is not their first language. They come from many different countries and many different cultures and have different attitudes and opinions about health in general.” Provider #3

3.2.2 Biological Issues—Comorbid illnesses, genetic issues, and memory challenges were biological concerns that were seen as important contributors to the stressors associated with having epilepsy.

“We have heard a lot about exterior stressors, but we had a neurologist point out to us that internal stressors can also cause seizures....And if he (PLWE) didn’t eat like a diabetic at a certain time his blood sugar would drop just enough that it would stress him.” Family #2

Genetic concerns about passing her epilepsy on to her two children was very much on the mind of one female PLWE:

“Two of my friends have had kids that have had seizures, so I know I’m probably going to pass this on to mine.” PLWE #9

One care provider spoke about the need to help PLWE who have memory challenges with aids to help them with managing their epilepsy and improve their quality of life:

“Lots of people with epilepsy have memory challenges and it’s important that they have strategies, tools in place to help them to remember to take their medication and manage all those different triggers that can improve their quality of life. And then the second thing would be some type of alert device especially if they’re having seizures at night to alert somebody in case they’re in a seizure during their sleep.” Provider #10

3.2.3 Medication Issues—Side effects of medications, as well as the long road to finding ones without any, were articulated by many PLWE and family caregivers. One parent of a teenage son with epilepsy talked about how the side effects of one epilepsy medication severely affected his teen age son:

“He has very severe anxiety and anger and periods of rage where he flies off the handle a lot, swears, and slams doors. His anger and his frustration and his actions and his swearing is not volitional; they’re a result of the side effects of the medication.” Family #3

And a PLWE described her own long journey to find the right medications that would control her seizures but had few side effects:

“I was on 20 different medications. Some controlled the seizures but the side effects of dizziness and other health issues weren’t worth it. One of them (medications) made me gain 100 pounds just like that. It’s kind of like is the juice worth the squeeze? You got to find the one that fits both ways; side effects and controlling the seizures!” PLWE #4

3.2.4 Financial Issues—As far as financial issues, Insurance coverage and employability were twin financial barriers that PLWE stakeholders felt that they had to grapple with on a daily basis and which added to their already stressful lives.

“Receiving disability payments (SSDI) puts your coverage for medications in jeopardy; earning too much money, puts your Medicaid coverage at risk.” PLWE #9

“I’d say mine is probably financial. I’m on SSDI but I have to remain off Medicaid for the amount that Medicaid doesn’t cover my medicine. Can’t really get employed to stay on Medicaid.” PLWE #1

“When I first went on disability, they wanted me to go get a job, just something menial. They said just go sit with a friend and have them pay you a couple bucks a week just to show that you’re employed to keep the Medicaid. But then you run into the stress of, okay if something happens and somebody pays me too much and it gets reported, that throws a monkey wrench into everything, so that stress is bad; you get your disability taken away!” PLWE #7

3.2.5 Access to Care Issues—Access to medications and healthcare providers was mostly dependent on transportation. However, lack of mass transportation in rural areas, and restrictions against driving proved to be major access barriers for PLWEs and their families in receiving epilepsy care:

“Just the rural nature of the state that I live in, sometimes people cannot get anywhere to pick up their medications. It’s quite different than urban settings where the pharmacy is more accessible.” PLWE #5

One care provider summed up the real-time access to care barriers that PLWEs and families in rural areas face every day:

“I find that in my area the nearest neurologists are at least 40 miles away from most of my patients, and they’re the ones typically that are referred to me for management, so that’s a resource issue. PLWE don’t have a good car, they don’t have the money, it’s an unexpected expense and, secondly I find that if they’re working they often will not report breakthrough seizures because in our state the law is that they cannot drive for six months after a seizure. And then that means even more economic hardship. I have some patients now that I’m aware that are likely returning to work and driving vehicles because they’re destitute for that financial support, but they technically should not be.” Provider #11

3.2.6 Epilepsy and Health Knowledge Issues—Care providers weighed in on what they thought was the lack of information and misinformation about epilepsy in rural areas:

“Well as the pharmacist, I’ll say that people do not understand medication and they don’t really understand side effects and it’s just all scary and if the seizures stopped, they ask why don’t I stop taking the medications?” Provider #13

“I would say misinformation is probably the biggest problem. There’s a huge misconception on how to use abortive medicine because it’s really indicated to prevent seizure clusters, not the current seizures.” Provider #8

3.3 Facilitators to Epilepsy Self-Management (Table 3)

The two overarching themes that arose from the focus group discussions about facilitators to epilepsy self-management were: 1) Lifestyle management and 2) Supportive others.

3.3.1 Lifestyle management—PLWE and family stakeholders cited diet and exercise as things that were being done to manage stress and decrease frequency of seizures:

“Switching our diet has helped a lot. Our physician recommended doing the modified Atkins for seizures, but my husband has been diagnosed with pre-diabetes so we have kind of switched over to doing Keto now. I feel like it helps a lot.” Family #4.

“I’ve got to have some type of physical activity. A lot of times I’d go run a couple or three miles a day for a workout. When I got a little older and couldn’t run anymore I’d split a lot of firewood, just anything that is a good hard physical activity just relaxes your system enough that’s awful close to taking medicines.” PLWE #6

Trying to reduce the stress of living with epilepsy was another form of lifestyle management practiced by some:

“I’ve had a number of traumatic events that have triggered my seizures, so trying to manage my stress levels by keeping on a regular sleep schedule and trying to control my anxiety helps a lot.” PLWE #9

For PLWE who were still in the workforce, creating a safe work environment was a very important topic of discussion. Disclosing to other people in the workplace that they had epilepsy, not only opened doors to communication, but also helped ensure their safety:

“I’ve worked a bunch of jobs, and one thing I found I had to do was tell people at work that I had seizures not because I was required by law, but for my own safety. Then they don’t freak out and overreact when I have one and can help me in case I have one.” PLWE #10

3.3.2 Supportive others—Having a strong support system was viewed by PLWE as the most important facilitator to self-management of epilepsy. They were especially grateful to the support provided by family and friends who, were not only instrumental in providing them with transportation to medical appointments, but also validated their self-worth:

“Yes, my parents are still my biggest support system. They’re the ones that drive me to the doctors and when they can’t, usually my boyfriend will step in.” PLWE #4

“My family has been great, and I asked my best friend about it and she said that epilepsy is just part of me. It’s not all of what I am. So, I think that people can make a big difference in your life.” PLWE #2

In addition to family and friends, epilepsy healthcare providers, organizations, and even pets, were also mentioned as sources of support by PLWE and their families:

“My last visit wasn’t in the office because of Covid, and my doctor sat on the phone with me for over an hour helping me deal with being recently diagnosed with epilepsy.” PLWE #5

“My son has epilepsy and I got a dog to provide support for his anxiety. When the dog senses he’s anxious, the dog goes to him and helps comfort him. Another thing that’s been really critical in terms of support has been a woman at the Epilepsy Foundation. She helped me with my son’s 504 plan, with working with the school, and with training about epilepsy. Without her and that role and that support, I never would have gotten through it!” Family #3

In order to be better informed about epilepsy, one family member pro-actively sought out information by attending epilepsy conferences. Her aim was to learn about new treatments for the disorder so that she could discuss them with her husband’s epilepsy provider:

“I go to the Iowa epilepsy conference every year, and that’s how I get most of my information. I learn from that information and then I take it to the neurologist. It’s like I have to find out from the conference what they don’t tell me. Now that’s a little messed up because you’d think it would be the other way around.” Family #4

3.4 Perceptions of the SMART Epilepsy Self-Management Program (Table 4)

The four overarching themes that arose from the focus group discussions on perceptions of the SMART intervention were: 1) Strengths of the program, 2) Challenges to implementation, 3) Suggestions for improvement, and 4) Suggestions to facilitate patient participation and retention.

3.4.1 Strengths of the program—All stakeholder participants were very enthusiastic about the SMART program and felt that it would fill a gap in epilepsy care in rural communities and improve medication adherence:

“During the neurology clinic visit the focus is on treatment and there’s just not enough time. This is the missing piece of really addressing and implementing self-management strategies that can be very meaningful for these patients. I think a SMART group would improve compliance and improving compliance, naturally decrease seizure frequency.” Provider #10

The use of Zoom conferencing, the group format, and the use of peer educators in the program, were seen as important factors by all stakeholder groups in decreasing isolation and providing interaction with others who had epilepsy:

“We just can’t meet people with epilepsy because we live so far from anything but we could get together on Zoom! Family #3

“I think one of the big benefits of SMART would be they’d have this small group of people who’d feel a little bit like a village. It’s just this feeling of I’m not alone and there’s a lot of other people who are going through the same sort of stuff. PLWE #7

“I see people in the acute phase when they may be first diagnosed and the shock of it! The thing’s going to change their life and there’s some stigma, but what has been helpful for them is to be able to meet with other patients who are a little bit further along the journey, so I think a peer educator is very important, in helping them be successful in managing their feelings about stigma and medication.”

Provider #14

3.4.2 Challenges to implementation—Care providers voiced concerns about rural residents having internet access, especially amongst low income people, but there was acknowledgement that phone access was a viable alternative to being able to participate in SMART:

“Some of our adults do have technology and are able to access it, but there are especially a lot of low income adults out there that don’t have the technology and it’s tough. They could still benefit through a phone visit.” Provider #8

“You also have to make sure that they have internet. I work at a district that is rural. They tend to not have great internet or great internet speeds in rural areas. If they can call in and they can use their phone, but data is also very expensive.” Provider #1

3.4.3 Suggestions for improvement—While some providers noted the difficulties with poor internet access, others felt the more relevant issue was that of providing support for PLWE in setting up and accessing zoom meetings in order to participate in SMART:

“Probably like 85% of households in Iowa have potentially really good internet. But what we found clinically, that doesn’t mean they can do a Zoom meeting. Just because they have high speed internet coming into their house doesn’t mean they have a computer with a functional camera, microphone, and know how to set it up.helping people get set up for Zoom type meetings would make a big difference. ...I think you would have some people that could join in that way that otherwise might not.” Provider #8

Although the curriculum was well received by all stakeholder participants, PLWE and family members suggested using larger print in the material related to the curriculum topics, sending the material in advance of each group session, by email and, for those without internet access, by postal mail. They felt that these measures would give them more time to familiarize themselves with the material and be more equipped to participate in group discussions. In addition, they suggested visuals related to curriculum topics be printed on individual pages. PLWE also suggested that additional topics such as emphasizing a set time for taking medications, and stressing the importance of pacing yourself, might be helpful additions to the curriculum:

“.. there might be people you put in this program that are old enough that they don’t know how to use the computer. So, having the curriculum sent to them beforehand is definitely a good idea.” PLWE #2

“Mainly emphasize to just stick with your medicine routine, and have a set time for everything and don’t wait.” Family #1

“...for the first two years after I got epilepsy. I didn’t take into account that I had epilepsy, until I had more seizures because I was doing more than I should be. So maybe mentioning something like that to whoever you have in the SMART program would be a good idea. Because I was a great student before, I expected it to continue even with the epilepsy, but there are certain things with the epilepsy that I just wasn’t able to do anymore. And I had to accept it.” PLWE #6

Provider stakeholder strongly felt that family members should be involved in the SMART program, either as participants with the PLWEs, or separately:

“Well some of the topics look like they could also be good education points for those family members or the caregivers....I don’t know if you’d want to do a full eight weeks with them but even just having some shorter more focused sessions that would apply more to the caregivers.” Provider #1

“...there’s a function called breakout rooms that you can use. The person in charge can send people into a room and you can designate ahead of time that this will be the caregiver’s room and you can bring them back together when you want to.” Provider #9

3.4.4 Suggestions to facilitate patient participation and retention—All stakeholder participant groups were quite enthusiastic about offering suggestions for recruiting PLWE for the epilepsy self-management classes. These included reaching out to community care providers and associations as referral sources, as well as distributing flyers and brochures describing the program:

“People who get admitted to the hospital with seizures are often times seen by a social worker. Maybe hospital social workers and rural communities have a way of referring patients who need extra counseling and it’s easy to get a list of rural hospitals. The other way of doing this is state board of pharmacies would have a list of rural pharmacies and that’s a way of getting access to pharmacies.” Provider #8

“Make sure that the epilepsy foundation has it for their annual walk, and their events that they do every year because there are literally thousands and thousands of people who are within that care group, so you can get it out to them.” Family #3

“Distributing flyers in grocery store bulletin boards, public health centers, public libraries, and senior centers, where people can see them.” PLWE #4

Others suggested referral sources that included churches, drug rehab clinics, and places where men typically congregate:

“I think in rural settings a lot of times the main social structure is the church. There’s usually one or two churches and so that might be someone to partner with”.
PLWE #6

“Also any drug rehab or any organization that work with people because substance abuse is an issue with people who have epilepsy.” Family #1

“If you’re looking to recruit men, go to VFW halls and barber shops, that’s where they congregate, and that’s where they talk about these issues between themselves.
Provider #14

Providers, particularly, felt that the sharing of stories and experiences with each other, as well as introducing educational activities during each session, would enhance engagement of PLWEs during the study. Additionally having the peer educators follow up with each PLWE between sessions would enhance retention:

“Well part of it is just sharing who they are, asking something about them and maybe find out that they have things in common with people in the group.”
Provider #4

“You could also do questions on polls on Zoom in the beginning on whatever you’re teaching or educating on that day. You know how many have ever tried dietary therapy, and then you can immediately show the graph of the poll. You know you’re taking a general poll and then that leads into your educational content.” Provider #7

“I think people really respond well to the peer educators. like right off the bat, and if there’s a way to kind of loop the peer educators in to reaching out to everybody for follow-up after each group, it really makes a difference in their commitment to the full eight weeks.” Provider #6

4. Discussion

Implementing and adopting a self-management program for PLWE requires considering many factors at the person, program, and system levels [14]. Engaging stakeholders in the refinement of an evidenced-based remotely delivered epilepsy self-management program, allowed the researchers to integrate insights from a variety of sources and interpretations, and facilitated validation through cross verification [28]. This process enabled the researchers to build a deeper understanding of barriers and facilitators to epilepsy self-management, and gather information and perceptions of the SMART program.

4.1 Barriers and Facilitators to Epilepsy Self-Management

Our findings that all stakeholder focus group participants overwhelmingly identified stress, stigma, financial issues because of disability policy, and medication side effects, as major barriers to epilepsy self-management, are consistent with those of studies of urban PLWE. In a study by Haut et al. [31] a patient perception survey about stress that was administered to a sample of PLWE (n=89) outpatients at an urban medical center in New York city, revealed that 64% of the PLWE reported the belief that stress increased the frequency of their seizures. Both major and minor stressors were reported with equal frequency. The majority

of the study population believed that stress and seizures are related and were willing to try stress reduction techniques for seizure control. The refined SMART study curriculum for rural/semi-rural PLWE devotes one of the eight sessions to promoting stress reduction techniques.

Because the impact of stigma on the lives of PLWE is often underestimated by healthcare workers [32], and epilepsy-related stigma has such far-reaching consequences, identifying factors associated with increased stigma in PLWE at high risk of poor outcomes might help inform care methods that reduce epilepsy burden. Using baseline data from the SMART study (described previously), researchers found that individual factors correlated with worse stigma were indicative of more severe or poorly controlled seizures (frequent seizures, worse seizure severity scores, more AEDs), mental health comorbidity (worse depression severity, other comorbidities) and factors related to individual functioning and perceived competency in managing their health (health literacy, health functioning, self-efficacy, quality of life). Multivariable linear regression found that worse quality of life, and having a mental condition were associated with more stigma ($\beta = 6.4$ and 6.8 , respectively), while higher self-efficacy, health literacy, and social support were associated with less stigma ($\beta = -0.06$, -2.1 , and -0.3 , respectively). These five variables explained 50% of stigma variation [33]. The refined SMART study curriculum for PLWE in rural/semi-rural communities focuses on psychiatric comorbidities, addresses low health literacy by having all written communication written at an 8th grade level, and employs effective health communication strategies about epilepsy misconceptions about stigma and on stigma coping.

In another study that used qualitative methods to develop a deeper understanding of the issues surrounding the refinement and implementation of a self-management intervention targeted towards urban PLWE with both physical and psychological co-morbidity, stakeholder focus groups composed of PLWE, healthcare professionals, and caregivers, (n=22) were conducted to identify barriers and facilitators to epilepsy self-management for this population. Similar to most of our findings, stakeholder participants in these focus groups identified stress, stigma, medication side effects, disability policy, lack of social support and knowledge about epilepsy, as barriers to self-management of their illnesses [34].

An important barrier cited by all the stakeholder groups in our study was the more limited access to epilepsy care provided by neurologists. There is a relative shortage of neurologists in many rural areas of the United States (often called neurology deserts), and primary care providers (PCPs) provide a large proportion of care for PLWE, but often lack the appropriate education and training to do so effectively [35,36]. To increase rural provider education about epilepsy, McDonald et al., [37] successfully piloted a 2-year tele-mentoring program which was effective in educating rural PCPs about epilepsy treatment. Out of the 164 participants, 97% reported greater interest in improving care for rural PLWE and 98% reported greater comfort and self-efficacy when treating PLWE. While this is an important step in improving access and clinical care for PLWE in rural areas, what appears unique to the PLWE in our study was their geographic isolation because of the inability to drive and the lack of public transportation. These factors further amplified social isolation by creating an additional barrier to maintaining friendships and, importantly, meeting other PLWE.

While PLWE in our study cited lifestyle management, such as diet and exercise, as helpful facilitators in managing stress and frequent seizures, the emotional and instrumental social support they received from family members and friends, was cited as the number one facilitator in management of their epilepsy. However, virtual self-management programs, like SMART, could help people feel less isolated, and less dependent on their families. At the same time, the power of the group process could increase confidence, improve self-management skills, and provide additional social support. Indeed, social support has been found to be a key mechanism that aids individuals in epilepsy self-management, as well as managing other chronic conditions [38–40].

4.2 Overall Perceptions of the SMART Program

The provider stakeholder respondents felt that the use of peer educators to teach and model self-management, was a particular strength of the program. Peers with chronic health conditions have access to lay expertise that is typically inaccessible to health care providers, and can have success in promoting health in populations characterized by health disparities [41,42]. In a systematic review of 13 qualitative and mixed methods studies on barriers and facilitators to implementation of epilepsy self-management programs, Lewinsky et al., [14] found that PLWE expressed a desire for a team composed of an individual with epilepsy and a clinician interventionist to deliver self-management education and support. Additionally, Blixen et al., [43] found that peer educators who took part as interventionists in a self-management program for people with mental illness and comorbid diabetes, felt their own knowledge about these illnesses increased, and their self-management skills improved.

Perhaps the most important finding was that all stakeholder groups were very enthusiastic about the remotely delivered SMART epilepsy self-management program, and felt that it would fill a void in epilepsy care in rural communities. To our knowledge, there is limited data on epilepsy self-management programs that have been implemented in rural areas. One self-management telephone-based program, HObased Self-management and Cognitive Training Changes lives (HOBSCOTCH), targeted cognitive dysfunction in an RCT of rural adults (n=66) with epilepsy. Results of the 8-session telephone and Web-based group program showed significant improvement in quality of life and cognitive functioning compared to wait-listed controls [44]. A group format intervention, Project UPLIFT, delivered via Web or telephone, evaluated the efficacy of a mindfulness-based cognitive therapy (MBCT) intervention, for preventing major depressive disorder (MDD) episodes in PLWE living in rural areas. In an RCT (n=128), the group format intervention showed the incidence of MDD episodes (new or relapse) from baseline was significantly lower in the intervention group compared to the TAU group as were depressive symptoms [45].

While these formative epilepsy self-management programs have been instrumental in targeting cognitive impairment and depression among PLWE in rural populations, SMART offers a broader approach to self-management by targeting those with recent negative health events (NHE) and a curriculum that covers general epilepsy management principles, treatments, minimizing epilepsy complications, strategies to cope with stress, stigma and double stigma (psychiatric co-morbidities), problem solving skills, nutrition, substance abuse and its effects on epilepsy, and communicating with healthcare providers.

4.3 Suggestions for Refining Smart

All stakeholders' suggestions for improvement/modifications to SMART were duly noted, and included minor changes to the curriculum, providing support for PLWE in setting up and accessing the Zoom meetings, as well as providing support for family caregivers within the program. According to Rosland and Piete [46], families often want to be involved in patient care but do not know what support roles would be most useful or what specific actions they can take on a day to day basis.

4.4 Limitations of the Study

Whereas our findings have implications for informing care delivery for PLWE living in rural/semi-rural areas, there are some limitations. Sample demographics do not include racial and ethnic minorities, but this is consistent with the demographics of the recruitment areas [47]. However, we do note that except for collecting information on duration of epilepsy, information on frequency, and severity of seizures and other clinical variables, is a limitation of our report. Although the sample size used in the focus groups were deemed to be appropriate for the purpose of qualitative analysis, it remains small and not necessarily representative of the broad population of PLWE. For example, all patients in this sample were white, most caregivers were female, and most health care providers were non MDs. This could limit the generalizability of the conclusions. 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. Nevertheless, these limitations are offset by the use of rigorous qualitative methods, which are consistent with guidelines outlined in the Consolidated Criteria for Reporting Qualitative Research (COREQ) [48] to improve the rigor, comprehensiveness, and credibility of focus groups. These self-report methods are direct, versatile, and yield information that would be difficult, if not impossible, to gather by other means.

4.2 Conclusions

The community-based participatory research approach used in this study enabled the study team to better understand the real time barriers and facilitators to epilepsy self-management, and elicit perceptions of the SMART program, from the perspectives of PLWE, families, and providers. Importantly, this information will enable modifications to the intervention protocol, and will pave the way for implementation of SMART in a rural and under-served population.

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HIGHLIGHTS

- Rural dwelling people living with epilepsy (PLWE) have limited access to healthcare
- Information on an evidenced based remotely-delivered self-management program was presented to key stakeholders (PLWE, family members, care providers) in a rural setting
- Key stakeholders felt strongly that his program could fill an epilepsy care gap in rural settings
- Key stakeholders provided suggestions for modification to the program curriculum for PLWE
- Key stakeholders provided suggestions for recruitment and retention strategies of subjects for a Phase 2 RCT

SESSION	TOPICS
Session 1	Orientation and introductions; Emphasize ground rules; Establishment of a therapeutic relationship; Facts and myths about epilepsy and general epilepsy management principles
Session 2	Relationship of epilepsy and stress; Stigma and “double stigma”; Strategies to cope with stigma; Introduction to personal goal- setting
Session 3	Treatments for epilepsy; Complications of epilepsy; Minimizing epilepsy complications; The importance of daily routine and good sleep habits
Session 4	Problem-solving skills and the IDEA approach (Identify the problem, Define possible solutions, Evaluate the solutions, Act on the best solution); Talking with your health care providers; Role play of communication with care providers
Session 5	Nutrition for best physical and emotional health; Substance abuse and its effects on epilepsy; Specific stress-management approaches
Session 6	Effects of exercise and being outdoors on physical and emotional health; Medication routines; Prioritizing medication side effects and discussing it with your clinician
Session 7	Social supports and using your available supports; Advocacy groups for epilepsy; A personal care plan to take care of the mind and body
Session 8	Normalizing your life in spite of having a chronic but unpredictable condition; Self-management as a life-style; Acknowledgement of group progress; Setting the stage for Ongoing Illness Management and Recovery (Step 2)

Figure 1.
SMART Self-Management Curriculum

Table 1:

Characteristics of the Sample (N=34)

Variable	PLWE Mean (SD) or N (%) N = 13	Family Caregivers Mean (SD) or N (%) N = 5	Care Providers Mean (SD) or N (%) N = 16
Age	48.5 (11.5), range 34–69	59.4 (9.55), range 49 – 69	48.33 (14.05), range 28 – 65
Gender			
Female	6 (46%)	4 (80%)	13 (81%)
Male	7 (54%)	1 (20%)	3 (19%)
Ethnicity			
Hispanic or Latino	0 (0%)	0 (0%)	2 (13%)
Race			
White	13 (100%)	4 (80%)	15 (94%)
Not Reported	0 (0%)	1 (20%)	0 (0%)
Black/African American	0 (0%)	0 (0%)	1 (6%)
Education Level			
College 4 years or more	2 (15%)	3 (60%)	—————
College 1–3 years	10 (77%)	2 (40%)	—————
Grade 12 or GED	1 (8%)	0 (0%)	—————
Employment Status			
Retired	3 (23%)	3 (60%)	—————
Employed for wages/Self-Employed	5 (38%)	2 (40%)	—————
Unable to work/Out of work for 1+ year	5 (38%)	0 (0%)	—————
Professional Role			
Primary Care Clinician	—————	—————	1 (6%)
Social Worker	—————	—————	2 (13%)
Epileptologist	—————	—————	1 (6%)
Neurologist	—————	—————	2 (13%)
Other*	—————	—————	10 (63%)
Income			
\$50,000 or more	5 (38%)	4 (80%)	—————
\$25,000 to \$49,999	2 (15%)	1 (20%)	—————
Less than \$24,999	6 (46%)	0 (0%)	—————
Insurance Status			
Private/Commercial	7 (54%)	5 (100%)	—————
Medicare	8 (62%)	2 (40%)	—————
Medicaid	5 (38%)	0 (0%)	—————
Relationship Status			
Married	7 (54%)	4 (80%)	—————

Variable	PLWE Mean (SD) or N (%) N = 13	Family Caregivers Mean (SD) or N (%) N = 5	Care Providers Mean (SD) or N (%) N = 16
Never Married	4 (31%)	1 (20%)	
Divorced/Widowed	2 (15%)	0 (0%)	
Age diagnosed with Epilepsy	15.88 (14.68), Range 1 – 47	_____	_____
Travel miles to see epilepsy provider	57.55 (41.85), range 1 – 116	_____	_____
Type of epilepsy provider seen			
Epileptologist	8 (62%)	_____	_____
Neurologist	5 (38%)		
Number of times you see an epilepsy provider in one year			
Every 3 months	1 (8%)	_____	_____
Twice per year	8 (62%)		
Once per year	4 (31%)		
Number of visits a PLWE has with you in one year	_____	_____	
0 – 5 visits			11 (69%)
5+ visits			2 (13%)
Not Reported			3 (19%)
Your relationship to the PLWE			
Spouse	_____	4 (80%)	_____
Parent		1 (20%)	
Years caring for your family member with epilepsy	_____	28 (21.92), Range 4 – 51	_____
Years providing services to PLWE	_____	_____	15 (11.86), range 1 – 35

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Table 2

Perceived Barriers to Epilepsy Self Management in a Rural Population (N=34)

THEMES	CATEGORIES
Psychological Issues	Stigma Stress Attitudes and culture
Biological Issues	Comorbid illnesses Genetic concerns Memory challenges
Medication Issues	Side effects Finding the right medication
Financial Issues	Insufficient insurance coverage Employability
Access to Care Issues	Access to transportation Access to medications Access to healthcare providers
Epilepsy and Health Knowledge Issues	Lack of information about epilepsy Misinformation about epilepsy

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Table 3

Perceived Facilitators to Epilepsy Self- Management in a Rural Population (N=34)

THEMES	CATEGORIES
Lifestyle Management	Diet & exercise Managing stress Creating a safe work environment
Supportive Others	Family & friends Care providers

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Table 4

Perceptions of the SMART Epilepsy Self-Management Program for a Rural Population (N=34)

THEMES	CATEGORIES
Strengths of the Program	Fills a gap in epilepsy care Comprehensive curriculum Use of peer educators Zoom format decreases isolation Group format provides interaction with others
Challenges to Implementation	Access to internet Access to cell phones
Suggestions for Improvement	Provide support to help access zoom meetings Curriculum issues Involve caregivers in meetings
Suggestion to Facilitate Patient Participation	Enhance recruitment strategies Enhance engagement and retention strategies

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