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Research Paper

# Understanding the perceived impact of a peer-led epilepsy self-management intervention in Uganda: a qualitative study

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ABSTRACT

*Objective:* To examine how adults with epilepsy in Uganda experienced epilepsy self-management, stigma, and care following participation in a peer-led intervention (SMART-U) compared to enhanced treatment as usual (ETAU).

*Methods:* This qualitative study was embedded within an ongoing randomized controlled trial at two university neurology clinics. A purposive subsample from both study arms completed semi-structured interviews at 13 (n = 16) and 24 weeks post-intervention (n = 16). Interviews explored perceived benefits and challenges of care, self-management behaviors, stigma and recommendations for improvement. Transcripts were analyzed using thematic analysis.

*Results:* Four themes emerged: barriers to self-management, self-management behaviors and attitudes, participant perspectives on care, and facilitators of self-management. Participants in both groups described significant structural and social barriers, including stigma, limited support, and challenges accessing care. However, SMART-U participants more frequently reported increased confidence, engagement in proactive self-management (e.g., stress management, planning around seizures), improved communication with providers, and greater ability to cope with stigma. In contrast, ETAU participants more often characterized epilepsy care as provider-driven, with fewer changes in attitudes or behaviors. Over time, SMART-U participants demonstrated clearer shifts toward self-efficacy and a more reflective understanding of epilepsy.

*Conclusions:* Peer-led self-management support may enhance engagement, coping, and self-efficacy among people with epilepsy in resource-limited settings. Addressing stigma and strengthening social and healthcare support may be critical for improving outcomes in low-middle income countries.

## 1. Introduction

Approximately 70 million people are affected by epilepsy worldwide, with a large percentage from low-middle income countries (LMICs), including Uganda [1,2]. Unfortunately, there are few neurologists in sub-Saharan Africa, making the provision of care for adults with epilepsy dire. People with epilepsy (PWE) from LMIC settings also face challenges such as social isolation, limited access to care, and lower epilepsy awareness, all of which hinder help-seeking behaviors and exacerbate epilepsy symptoms [3–6]. Individuals in LMICs experience disparities and challenges to getting appropriate and comprehensive epilepsy care [6–8], leading to poorly controlled epilepsy, reduced quality of life

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(QOL), and use of crisis-oriented care that burdens strained public healthcare systems.

Risk factors for suboptimal seizure control include limited social support, poor medication adherence, stigma and mental health comorbidities (e.g., depression, substance abuse) [9,10]. In a study of Ugandan adolescents with epilepsy, high household poverty and dropping out of school were associated with suboptimal QOL and severe epilepsy consequences (e.g., accidents/injury) [5]. Given the limited socioeconomic means coupled with poor access to anti-seizure medications (ASMs), epilepsy self-management support is less available to PWE in rural settings [11]. Additionally, in Africa, epilepsy is not only a medical diagnosis but also a stigmatizing label that involves the perception of PWE as contagious, insane, evil, and a target of prejudicial behavior [6,12,13]. In LMICs, societal epilepsy stigma is pervasive, affecting nearly 70% of PWE and their families [14]. Sociocultural beliefs, including self-stigma (i.e., internalized attitudes aligning with societal stigma) and spill-over stigma (i.e., stigma that extends to the families of an affected individuals) potentially help by the PWE and/or their immediate family, may further worsen QOL and functioning. It is important to educate and empower patients, especially those from disadvantaged backgrounds, and engage them more fully in treatment decisions and epilepsy self-management [15,16].

Healthcare extenders, including nurses, peers, caregivers, and family members could be critical agents for change in sub-Saharan African, where resources are limited. One way to effect this change is by providing self-management interventions via these healthcare partners to reduce morbidity and mortality among PWE. Epilepsy self-management refers to a patient managing the treatments and day-to-day lifestyle changes associated with epilepsy, which impacts epilepsy related outcomes (e.g., seizures). The program, **S**elf-**M**anagement intervention for **R**educing **T**he epilepsy burden among **U**gandans (SMART-U), is an adjunct to standard epilepsy care that is informed by chronic disease self-management principles and techniques. SMART-U was piloted in Uganda with demonstrated feasibility, acceptability, and preliminary efficacy [17]. The SMART-U intervention uses peer educators to teach a self-management curriculum focused on patient and family needs, problem-solving, and attention to emotional and role management. Peer Educators share pertinent lived experiences that are important to guide care and self-management among PWE. The next logical step was to conduct a randomized controlled clinical trial (RCT) of SMART-U compared to an enhanced treatment as usual (ETAU) group. It was hypothesized that the SMART-U group would have improved QOL, fewer seizures and greater improvements in depression and functional status compared to ETAU. The methods of this trial have been published elsewhere [18], and the primary and secondary outcomes are still pending, as longitudinal data collection is still ongoing. However, one important component of the study was to conduct qualitative interviews with a subset of participants in both treatment groups to assess the perceived impact of SMART-U and ETAU on study participants.

Qualitative research remains an integral component to developing health promotion interventions in special populations [19]. While RCTs can demonstrate that an intervention leads to better disease control, qualitative research can provide insight into "why" and "how" the intervention succeeds or doesn't succeed [20,21]. In-depth interviews on perceived benefits vs. burdens as well as barriers/facilitators to SMART-U and ETAU were conducted across two Ugandan sites at two time points (13 and 24-weeks post intervention). Given the corrosive and persistent nature of stigma on QOL among PWE, input and recommendations on specific strategies regarding ways to potentially mitigate stigma in families and communities were also assessed. Informants included 13 patients from SMART-U and 13 patients from ETAU. Contextual data from these interviews facilitate understanding of the processes that impact the RCT quantitative outcomes [19]. Thus, the aims for the current study were to 1) compare experiences of participants in the SMART-U and ETAU interventions, 2) explore changes in perceptions of the intervention from 13 to 24 weeks, and 3) inform optimization and scalability of the SMART-U intervention for future trials.

## 2. Methods

### 2.1. Overall study design

The larger RCT, which occurred at two university hospital neurology clinics in Uganda and is ongoing, randomized participants into two groups: 1) intervention (SMART-U) or 2) ETAU. The SMART-U group received 12-weeks of intensive group-based education sessions co-facilitated by a nurse and trained peer educators around a variety of topics (e.g., medication adherence, stress management, communication, stigma coping, building social support) and 12 weeks of remotely accessed telephone calls; ETAU group received usual care with supplemental education materials and eight brief phone calls with a nurse spaced across six months (i.e., approximately biweekly during months 1 and 2, and monthly thereafter) to reinforce materials from written information provided and answer questions as needed. Both groups participated in SMS-based seizure monitoring throughout the study period. Of note, the study utilized different nurses in the delivery of SMART-U and ETU interventions to minimize contamination across study arms. The primary study aims were to determine the acceptability, feasibility, and efficacy of SMART-U compared to ETAU, with the primary outcome being changes in seizure frequency from 24-weeks pre to 24-weeks post follow-up. This larger RCT is ongoing and primary and secondary outcomes will be published in the future.

### 2.2. Qualitative study design

This qualitative study employed a descriptive, interpretive design using semi-structured, in-depth interviews. Data were collected from a purposive subsample of participants enrolled in the SMART-U randomized controlled trial. Interviews were conducted at post-treatment and 24-weeks post-treatment to capture participant perspectives following exposure to the intervention and to explore how experiences evolved over time.

### 2.3. Participants

Adults (≥18 years) with a confirmed clinical diagnosis of epilepsy were enrolled in the trial at neurology clinics at Mulago National Referral Hospital and Mbarara Regional Referral Hospital in Uganda. Eligibility criteria for the larger study included a history of at least one seizure in the prior six months, current treatment with anti-seizure medication, ability to provide informed consent, and capacity to participate in study procedures. Individuals with dementia, those who were pregnant, or those unable to engage in study activities were excluded.

Data collection for the larger trial is ongoing; recruitment goals include enrolling a total of 190 participants (n = 95 SMART-U and n = 95 for ETAU). For the current study, participants were purposively selected from both trial arms (SMART-U and ETAU) to ensure representation across intervention condition, biological sex, age, and rural versus urban residence. Participants were invited to participate in qualitative interviews, consistent with recommended sample sizes for in-depth qualitative inquiry and sufficient to achieve thematic saturation [22]. At each qualitative assessment point (Week 13 and Week 24 for both SMART-U and ETAU), interviews were conducted with 16 participants, evenly split between the SMART-U (n = 8) and ETAU (n = 8) treatment arms (50% per group). Of note, qualitative data for two participants (n = 1 Week 13 and n = 1 Week 24) were excluded from thematic analyses due to having multiple individuals involved in the interviewing, making it difficult to discern participant feedback. In addition, three participants from each treatment condition participated

in both Week 13 and Week 24 interviews; thus, the current study consists of 24 unique participants.

### 2.4. Procedures

All study participants provided written informed consent at enrollment for participation in the parent trial. Additional verbal consent for audio recording was obtained prior to each qualitative interview. Interviews were conducted at Week 13, which represents post-treatment of the SMART-U group and ETAU individual sessions, and again at Week 24, corresponding to the final follow-up visit.

Interviews were conducted by trained research staff with experience in qualitative interviewing and familiarity with epilepsy care in the local context. All interviews took place in person in a private setting at the clinic. All interviews were audio-recorded, transcribed verbatim and then translated to English by local staff in Uganda. Transcripts were de-identified prior to analysis to protect participants' confidentiality.

### 2.5. Qualitative data collection

Semi-structured interview guides were used to explore participants' perceptions of the intervention or usual care, including perceived benefits and burdens, barriers and facilitators to participation, changes in self-management behaviors, experiences with seizure control, emotional and social impacts, and recommendations for improving the program. Interview guides were adapted from prior self-management research conducted by the study team and aligned with the Integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework [23] to capture individual, contextual, and implementation-related factors (e.g., prompts about relationships with providers, learnings from group sessions, perspectives on involvement from peer leaders and group facilitators). Interview guides were flexible, allowing interviewers to probe emergent topics while ensuring consistency across participants and time points. Main domains of interview content included self-management (e.g., What kinds of things have been giving you trouble or gotten in the way of you taking care of your health?), stigma (e.g., Can you tell me about your experiences with stigma related to your epilepsy?), care experiences (e.g., Have you seen a traditional healer for your seizures/epilepsy?), and recommendations (e.g., What kinds of things are you doing now to manage your epilepsy that you didn't before being in the SMART-U groups?).

### 2.6. Data analysis

Transcripts were uploaded and managed using Dedoose [24], a computer-assisted qualitative data analysis software. Data were coded by three women (SWW, FS, and ACM) from White, Latine, and South Asian backgrounds, including two doctoral level psychologists and one master's-level trainee, reflecting intersecting positions of privilege related to education, healthcare access, and institutional authority. Although all coders conduct clinical and research work with individuals with epilepsy, none share this lived experience, and generational and professional differences were acknowledged during the coding process to promote reflexivity during analysis. Differences in nationality, race, cultural setting, and professional status between Ugandan participants and the coding team were also recognized as potential influences on interpretation. To support cultural validity, emerging findings were shared with local Ugandan investigators, whose feedback and perspectives informed interpretation and helped ensure findings remained grounded in local context.

Data analysis was guided by Braun and Clarke's thematic analysis approach. Two members of the research team (SWW & FS), both trained in qualitative methods and familiar with the SMART-U intervention, independently coded the transcripts and worked collaboratively throughout the analytic process. The coding process was a hybrid between deductive and inductive coding; initial codes were based on the semi-structured interview guide and discussed collaboratively to develop a consensus-based coding framework with clear, mutually exclusive code definitions, and additional codes emerged inductively. Coding discrepancies were reviewed and resolved by a third coder (ACM) through discussion to achieve consensus, and the coding framework was refined iteratively as analysis progressed. Discrepancies during the analytic process were discussed to consensus to achieve 100% agreement [22]. Following coding, coded text segments were organized into broader categories and themes through constant comparison across participants, time points, and treatment conditions. Analytic memos were used to document reflexivity, emerging interpretations, and relationships among themes. Codes were moved to themes following team meetings and thematic mapping (see Fig. 1). Analyses continued until thematic saturation was reached and no new themes emerged in the last four interviews across treatment conditions and timepoints.

### 2.7. Ethical considerations

The larger trial, including qualitative procedures, were approved by the relevant Institutional Review Boards in Uganda (i.e., Makerere College of Health Sciences − School of Medicine Research and Ethics Committee) and collaborating institutions (i.e., Case Western Reserve University School of Medicine (CWRU)). Participants were informed that their participation in interviews was voluntary and would not affect their clinical care or involvement in the parent study. All data were stored on a protected drive, and identifying information was removed from transcripts prior to analysis.

## 3. Results

Participants at Week 13 had a mean age of 28.6 years (SD = 14.6), while those interviewed at Week 24 were slightly older on average (M = 33.3 years, SD = 12.8). Biological sex distribution differed across time points. At Week 13, participants were predominantly female (63.5%), whereas the Week 24 sample included a greater proportion of males (56.3%). Participants represented a range of residential contexts, with most living in peri-urban or rural areas at both time points. Educational attainment was generally low to moderate, with the majority of participants reporting secondary level education. Marital status varied across the sample, with single status most common at both assessments, followed by married participants, and smaller proportions reporting separation or widowhood at Week 24. Sample characteristics for both ETAU and SMART-U groups for Weeks 13 and 24 are displayed in Table 1.

### 3.1. Overview of thematic findings

Qualitative interviews with participants enrolled in the SMART-U and ETAU arms yielded four overarching themes across both treatment conditions and timepoints: (1) barriers to epilepsy self-management, (2) current self-management behaviors and attitudes, (3) participant perspectives of the intervention, and (4) facilitators of self-management. Themes were identified at both Week 13 and Week 24, allowing comparison across intervention conditions and over time (See Table 2).

While participants in both SMART-U and ETAU described persistent structural and social challenges related to epilepsy care, the nature, frequency, and framing of themes differed by group, particularly with respect to stigma, perceived support, communication with healthcare providers, and confidence in self-management strategies.

### 3.2. Barriers to epilepsy self-management

#### 3.2.1. Seizure-related and mood-related challenges

Participants in both arms described seizure-related challenges, including interference with work, household responsibilities, and social

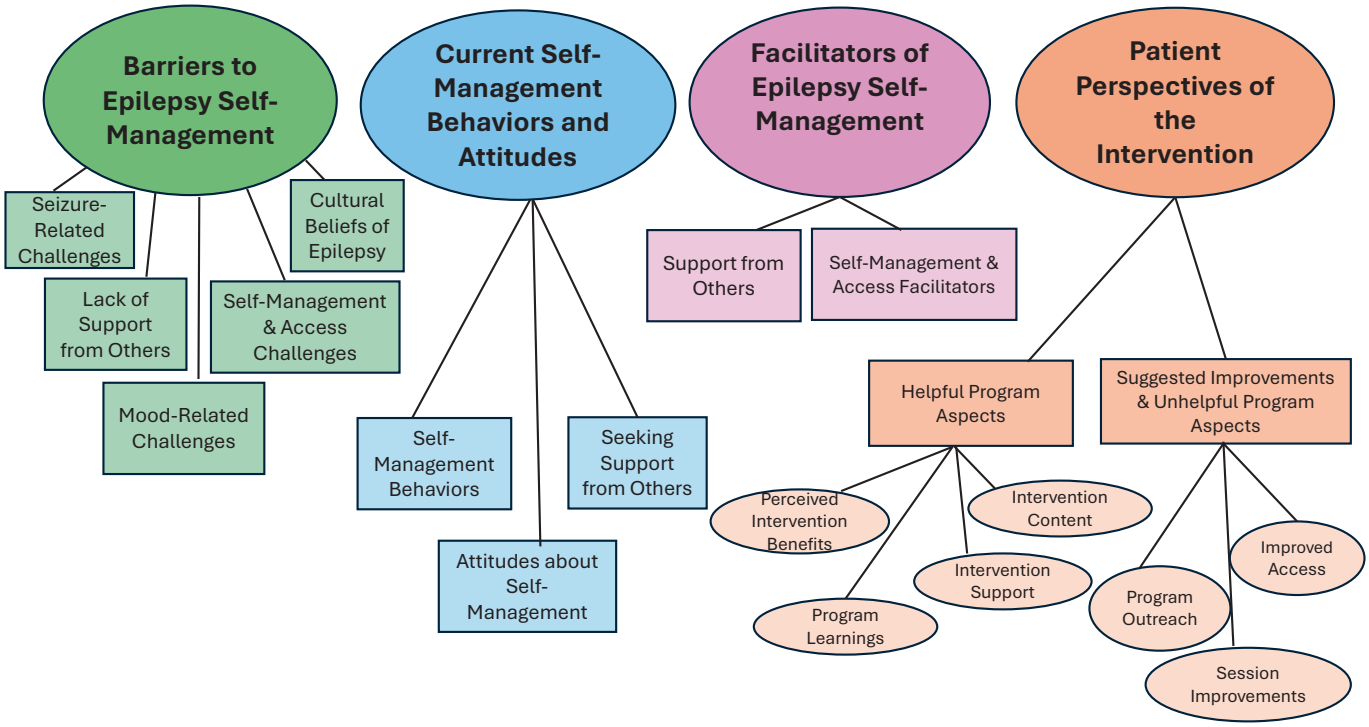


**Fig. 1.** Thematic map of SMART and ETAU thematic categories, themes, and subthemes.

**Table 1**
Participant demographics.

| Demographics | *Week 13 (n = 16)* *M (SD) or n (%)* | *Week 24 (n = 16)* *M(SD) or n (%)* |
|---|---|---|
| Age (years) | 28.63 (14.63) | 33.31 (12.84) |
| Treatment Arm | | |
| • Enhanced Treatment As Usual (ETAU) | 8 (50%) | 8 (50%) |
| • Treatment (SMART-U) | 8 (50%) | 8 (50%) |
| Sex | | |
| • Male | 6 (37.5%) | 9 (56.3%) |
| • Female | 10 (63.5%) | 7 (43.8%) |
| Location | | |
| • Urban | 5 (31.3%) | 4 (25%) |
| • Peri-Urban | 8 (50%) | 6 (37.5%) |
| • Rural | 3 (18.8%) | 6 (37.5%) |
| Education Level | | |
| • Primary | 3 (18.8%) | 4 (25%) |
| • Secondary | 10 (62.5%) | 11 (68.8%) |
| • Tertiary | 1 (6.3%) | 0 (0.0%) |
| • University | 2 (12.5%) | 1 (6.3%) |
| Marital Status | | |
| • Single | 9 (56.3%) | 7 (43.8%) |
| • Married | 5 (31.3%) | 5 (31.3%) |
| • Separated | 2 (12.5%) | 3 (18.8%) |
| • Widowed | 0 (0.0%) | 1 (6.3%) |

participation, as well as fear of injury and unpredictability of seizures. These challenges were commonly endorsed at Week 13 in both SMART-U and ETAU. By Week 24, though seizure-related barriers remained present, participants in the SMART-U group more frequently described improved ability to anticipate or manage seizure impact, whereas ETAU participants continued to describe seizures as largely uncontrollable and disruptive.

Mood-related barriers, particularly stress, worry, and emotional burden associated with epilepsy, were reported across both groups. Participants in the SMART-U arm more often linked mood symptoms to specific triggers (e.g., stress, lack of sleep, stigma), whereas ETAU participants tended to describe mood difficulties in more generalized terms. Across groups, mood-related barriers were less frequently emphasized at Week 24 compared to Week 13, though they did not fully resolve.

### *3.2.2. Cultural beliefs, stigma, and epilepsy misconceptions*

Stigma and culturally rooted beliefs about epilepsy emerged as a central barrier, particularly at Week 13. Participants in both groups described epilepsy as a stigmatizing condition associated with fear, shame, social exclusion, and misconceptions about contagion or moral wrongdoing. Participants noted both enacted (e.g., being told to leave group events or gathering places due to stigma regarding epilepsy) and anticipatory (e.g., avoiding social interactions with others due to stigma-related worries) stigma related to epilepsy. In addition to creating social isolation, these beliefs also affected disclosure of epilepsy diagnosis, help-seeking behaviors, and engagement with healthcare for epilepsy-related concerns.

Notably, SMART-U participants more frequently discussed stigma in reflective terms by Week 24, describing increased awareness of stigma and strategies for responding to it within families and communities. In contrast, ETAU participants continued to describe stigma as an external, largely immutable force, with fewer references to coping or mitigation strategies over time. A subset of participants in both arms described intentionally concealing their diagnosis to avoid discrimination. This was more frequently endorsed among ETAU participants at both timepoints.

### *3.2.3. Limited social support and access challenges*

Participants in both groups reported limited support from family members, friends, and employers, particularly early in the intervention period. At Week 13, lack of support was frequently described as exacerbating isolation and complicating medication adherence and clinic attendance.

Barriers related to healthcare access and self-management, including transportation difficulties, cost of care, medication availability, and challenges navigating the healthcare system, were among the most frequently endorsed themes across both arms. Although these access challenges persisted at Week 24, SMART-U participants more often described improved communication with providers and increased confidence in managing access-related barriers compared to ETAU

**Table 2**
SMART-U and ETAU themes, subthemes, and sample quotes.

| Week 13 | Week 24 |
|---|---|
| **Thematic Category 1: Barriers to Epilepsy Self-Management** | |
| **1a. Seizure-Related Challenges:** *Participants experiencing seizure interference and negative outcomes resulting from their epilepsy which impacts their daily living.* | |
| ETAU (n = 6): I also failed to finish school because of epilepsy, and this makes me sad. I want to speak English very well, but I can't because I didn't go to school. | ETAU (n = 5): I can now be left alone and be okay, but before the program, it was not possible because I could get seizures every 30 min. |
| SMART-U (n = 6): I started getting attacks when I began working. When I was still in school, I wouldn't fall down, but when I started working, the attacks began. I remember I would get an attack in class and fail to write… By the time I finished my education, the condition had worsened. | SMART-U (n = 5): Like the work that I do at home, it goes beyond my own strength, and I get a lot of headaches and sometimes a seizure comes. Sometimes you even fail to get the time to sit. |
| **1b. Mood-Related Challenges:** *Participants experiencing various mood-related challenges (*e.g.*, stress, anger) resulting from their experience with seizures or as a result of their epilepsy.* | |
| **Week 13** | **Week 24** |
| ETAU (n = 4): I had a lot of things stressing me then. Every time I worry so much about something, I start feeling dizzy, seeing things upside down, and then I start to feel the convulsions coming. | ETAU (n = 5): I used to be very sad. I would wake up, and I would get attacked (get seizures). So now I am controlling myself to be happy. |
| SMART-U (n = 6): I had a lot of anger due to the stress I was having, and this would eventually trigger my epilepsy. | SMART-U (n = 6): I was stressed because I had an illness that I did not know could be healed. I did not even know how to control it. |
| **1c. Cultural Beliefs of Epilepsy:** *Participants' experiences with stigma, cultural beliefs, and common misconceptions related to epilepsy.* | |
| **Week 13** | **Week 24** |
| ETAU (n = 7): Then they said, "Let us first go for prayers." They went there (to church), but nothing was changing… they told me that maybe those things were from hatred…they were like, 'Now you have the curse.' | ETAU (n = 4): We started going to traditional healers, shrines…They used to say that it wasn't epilepsy because if it was, I would be defecating and urinating on myself. So, they concluded that it was witchcraft that someone did to get money. |
| SMART-U (n = 8): …I cannot tell anyone who is outside our family. I cannot tell the neighbors either, because they do not help me. | SMART-U (n = 5): When people get to know that you have epilepsy, they'll keep insulting you, saying, 'That one had epilepsy!' |
| **1d. Lack of Support from Others:** *Participants not receiving adequate support or help from friends, family or their community.* | |
| Week 13 | Week 24 |
| ETAU (n = 3): My parents quit taking care of me. I came here for treatment after my parents gave up on getting me treatment for my epilepsy. | ETAU (n = 3): However, this is Africa; people may not support you all the time because they have a lot to do and they have other things to attend to. If someone supports you today, they might easily stop taking care of you after you have woken up. I know that since I can talk and walk, they might not easily understand that I'm not operating fully. When they see me working, they always think, 'Now that he can work, he can struggle for himself.' |
| SMART-U (n = 8): …my father stopped buying these drugs for me…He says, 'Those are your problems…' He doesn't support me in any way. Everything has to be done by my mother, and she gets overwhelmed with all the responsibilities she has. | SMART-U (n = 5): Like now, I have a one-year-old baby that needs to eat and drink. My husband is not giving me the money, and he is telling me to be the one to get the money and buy what the baby wants to eat and drink. I don't have the money, I don't work, and I end up getting stressed, which in the end sometimes causes me to seizure. |
| **1e. Self-Management & Access Challenges:** *Participants struggling with self-management skills related to epilepsy and health (e.g., medication adherence, consistent and rich diet, drinking water).* | |
| Week 13 | Week 24 |
| ETAU (n = 6): I stopped taking my medicine for like 3 months. I called my mother and I told her that the illness that was disturbing me had disappeared, and I didn't feel any problems… My mother got angry and said 'Why did you stop taking your medicine?' And I told her, 'I thought that I was better!' This is why I resumed my treatment. | ETAU (n = 6): Another thing is embarking on alcohol, and I start forgetting to take my medications. |
| SMART-U (n = 8): As a child, I never had any illness that required me to swallow medicine as much as I do with this one. I have to swallow medicine every day, something I am not used to. | SMART-U (n = 8): The biggest challenge I had to manage the illness was that I was not taking my medicine like I was supposed to. When I first started my treatment, I never got seizures, but I later quit taking it, and I started having seizures again. |
| **Thematic Category 2: Current Self-Management Behaviors & Attitudes** | |
| **2a. Self-Management Behaviors:** *Behaviors that promote self-management broadly of epilepsy (*e.g.*, adherence, exercise, anticipatory action, avoiding seizure triggers, improving nutrition, stress management)* | |
| Week 13 | Week 24 |
| ETAU (n = 7): I now eat enough food and on time because I realized it's one of the things that trigger my convulsions. | ETAU (n = 7): It has been several yeas (since drinking alcohol)… the first doctor who attended to me told me, 'Drinking alcohol will affect your brain,' so I quit. That's what has enabled me to come this far. |
| SMART-U (n = 8): I used to take my medicine in the morning and in the evening, but now, I am taking it in the morning, at lunch, and in the evening. | SMART-U (n = 8): One of the health providers asked, 'Are you taking your medicine well?' And I told her, 'Medicine is now part of my life. It is food that I eat every day.' I make sure I never run out of my medicine, and I have a bag where I keep it so as to always have it with me. We gained a lot from the program. |
| **2b. Attitudes about Self-Management:** *Participants' attitudes around their self confidence and independence with managing and coping with their epilepsy.* | |
| Week 13 | Week 24 |
| ETAU (n = 7): Interviewer: Anything else that gives you that confidence? Respondent: Nothing. What makes me confident is taking medicine as instructed by the doctors. | ETAU (n = 7): I am confident, and if you are confident, you can do whatever you can to achieve your goals. |
| SMART-U (n = 8): I feel like 80% confident, because my condition in the past is not the same condition in which I am right now. | SMART-U (n = 8): You have to be confident that this disease can heal, and if it does not, you need to stay on treatment. |
| **2c. Seeking Support from Others:** *Participants seeking support from friends, family, and the community.* | |
| Week 13 | Week 24 |
| ETAU (n = 3): Interviewer: What do you do to avoid overthinking? Respondent: Meeting up with my friends who have the same illness so that we can hear from one another in managing the illness. | ETAU (n = 1): This time, I can talk about how I am feeling, and they look for ways to help me. |
| SMART-U (n = 4): You might get people who can help you. Also, whenever you isolate yourself, you think negatively, but when you're close to some people, they can help you out. | SMART-U (n = 2): When you get a problem, you tell a friend that this and this has happened to me, then you feel free. |
| **Thematic Category 3: Facilitators of Epilepsy Self-Management** | |
| **3a. Support from Others:** *Participants receiving support from their friends, families, and community that support epilepsy care* | |
| Week 13 | Week 24 |
| ETAU (n = 7): When I was at home, I was just eating beans and posho. But when I told my grandmother what we learnt here, she now brings me beef, groundnuts, and bananas. Even when I want to eat just rice, she brings me rice. | ETAU (n = 7): Even my father promised me that, even if I am married, he will continue buying me the tablets…He's also buying me a place to make sure that even if he's not around, there is something to take care of me. |
| SMART-U (n = 8): It was mostly my parents who supported me. My mother encouraged me to swallow my medicine despite not having a clue what or how I was supposed to swallow the medicine. When this program recruited me, I had to come with my mother, so she got to | SMART-U (n = 8): My mother learned how to take care of me, especially whenever a seizure happened. She knows what to do in such situations, and she also encourages me to swallow my medicine. She also educates people that this illness is not as it is believed to be. |

(*continued on next page*)

**Table 2** (*continued*)

| Thematic Category 1: Barriers to Epilepsy Self-Management | |
|---|---|
| learn a lot of things about how to help me when the seizures come. | |
| **3b. Self-Management & Access Facilitators:** *Participants with access to necessities for epilepsy care (*e.g.*, purchasing medication, transportation to clinics)* | |
| Week 13 | Week 24 |
| ETAU (n = 6): I don't buy them (prescribed epilepsy medication) in small amounts; I usually buy them in four boxes, and each box has 10 strips. By the time I come back to the clinic, I still have some left, so I just top up on what I have left. | ETAU (n = 7): I put my drugs on the table where I can see them. Also, my wife always reminds me before I go to bed that I should take medicine. Even my children say, "Daddy, you have to take your medicine," because they know that I have to always take my medicine. |
| SMART-U (n = 8): I don't use an alarm, but my pastor reminds me in the morning. And if we spend the night together in the church, she'll give me food and tell me, "At exactly eight, swallow your medicine, don't miss." She even asked me, "If you need a clock, I can provide it so that you don't forget to swallow the medicine." | SMART-U (n = 6): I talked to my mother and she sent me to a doctor that she knew. When I went there, the doctor brought me here to the hospital, and I started getting treatment. |
| **Thematic Category 4: Participant Perspectives of the Intervention** | |
| **4a1. Unhelpful Program Aspects & Suggested Improvements** | |
| **4a1.1. Intervention Content:** *Intervention Content that SMART participants found to be challenging to implement or unhelpful.* | |
| Week 13 | |
| SMART-U (n = 3): I have told you that the only thing that has not been so helpful is the diet. It is hard to implement, especially in Uganda, because some people are not able to even get something to eat. Some people work in hotels and are going to ask their bosses for special food. | |
| **4a1.2. Program Communication:** *Communication challenges (*e.g.*, mobile health) SMART participants described experiencing during participation of the intervention.* | |
| Week 24 | |
| SMART-U (n = 5): The only challenge I faced was that they used to send the messages to my Airtel number, and I had to respond to an MTN number. But since it was for my own benefit, I got to know that the number we were responding to was registered on WhatsApp, so I would respond to them via WhatsApp. | |
| **4a2. Suggested Improvements** | |
| **4a2.1. Address Lack of Access:** *Participants expressed need for the program to address the lack of access (*e.g.*, limited medication access, increasing providers, bridging communication) impacting epilepsy care.* | |
| Week 13 | Week 24 |
| ETAU (n = 5): I would love that when you call the patient, you also go ahead and call the caretaker or the parent, so that they can tell you more of how the patient has been doing. | ETAU (n = 6): I don't know how they always diagnose this illness, but in my case, I was admitted to different departments before they brought me to the neurological clinic. I wish I had started from this department when I first got the illness; that way, I wouldn't have wasted all my resources. The first time I came here, they took me to the HIV clinic, then they took several other departments, and I was asked for very expensive tests. |
| SMART-U (n = 5): You have to engage the healthcare providers so that they can let people know about this program. The challenge is that most people are busy working, so joining might be tricky. I think healthcare providers at our clinic don't even know that this program is running. | SMART-U (n = 4): Another thing is that you add for us on the transport because all of us come from different areas. Sometimes you find that the transport they have given you doesn't take you back to your destination. |
| **4a2.2. Program Outreach:** *Participants ideas for increasing outreach to other patients with epilepsy in the local community.* | |
| Week 13 | Week 24 |
| ETAU (n = 7): I would want patients in other health facilities to get the information in this program because it will encourage them…It could give them more hope and encouragement. You might find that someone who had lost hope is improving. This program should have branches in different facilities. | |

**Table 2** (*continued*)

| Thematic Category 1: Barriers to Epilepsy Self-Management | |
|---|---|
| SMART-U (n = 8): I think you should use the internet and websites. Make sure the website can be understood by a lot of people. You should include what the SMART program is all about and which people benefits from it. Tell people how they can access the program and the benefits of being part of the program. | SMART-U (n = 8): You can advertise on radios social media. Someone can get interested, and they join. You can also take it to villages because they might not know about this program, and they don't listen to the radio. You can go to schools or hospitals and meet people there and then share your contacts so that they call you when they are ready to join. |
| **4a2.3. Session Improvements:** *SMART-U participants ideas for improving SMART intervention session (*e.g.*, number of sessions, length of sessions/program).* | |
| Week 13 | Week 24 |
| SMART-U (n = 8): I once told the health provider that the sessions were too short and few. We had been coming here every week for the past 8 weeks, but it would be best if we met twice a week. | SMART-U (n = 6): I would suggest that after a certain amount of time, we resume the sessions… They should be redone every 6 months to refresh our minds on what we have studied. |
| **4b. Helpful Program Aspects** | |
| **4b1. Intervention Content:** *Content aspects (*e.g.*, written content, session length/timing) participants found helpful.* | |
| Week 13 | Week 24 |
| ETAU (n = 3): They told us to engage in activities that help reduce stress, for instance, enjoying social hours with some of our friends, and in the evening, running around. | |
| SMART-U (n = 8): They were okay because they taught us everything we were supposed to do—like how to take care of ourselves, how to talk to others, things like that. They were in a simple format. They also gave us some papers so that whenever I find someone with a similar problem, I can give it to their parents. | SMART-U (n = 8): The SMART program taught us to get along with people in the community, to be confident while sharing our challenges, good nutrition, and what we have to use to manage our health. Generally, we have benefited a lot compared to before we joined the program. The program changed me… I learned how to take care of myself… |
| **4b2. Intervention Support:** *Intervention support from peer leaders, health providers, and other intervention staff that participants found helpful.* | |
| Week 13 | Week 24 |
| ETAU (n = 6): The doctors treat us fairly, to be honest… For instance, when we attend, we are treated equally… | |
| SMART-U (n = 8): We benefited from them (peer counselors) because they were also guiding us. For example, our peer educator told us that since he joined the group and started taking medicine, he has gone three years without seizures. Now, I am sure that as long as I keep taking my medicine and being settled, I will not get any seizures. | SMART-U (n = 8): We are lucky that we got health providers who brought us together in a group to inform us about epilepsy, how to manage it, and also comfort us. |
| **4b3. Perceived Benefits of Participation:** *Overall positive program experience and additional aspects of program participation (*e.g.*, improvements with health and self-efficacy, being fed/paid as a result of participation) that participants found helpful and supportive.* | |
| Week 13 | Week 24 |
| ETAU (n = 5): When I started being consistent with the treatment, the disease only manifested once in a while; it would take a while. When I became consistent with my treatment, I didn't get any epileptic attacks for 3 or more years. | ETAU (n = 11): At first, seizures would happen like thrice in 2 weeks, it would come three times. But when I started getting treatment, I would get it like five times a day. I would fall down all the time…But when I told the health providers that I was still getting them, they changed some tablets, and I started getting okay. So now it only happens once, and I can go months without seeing any seizures. |
| SMART-U (n = 8): In our group, the health providers used to give us something to eat after the classes, so it was really beneficial. They also provided us with transport. | SMART (n = 8): [The SMART-U program] has helped me to overcome this illness and also understand how to manage it, since it is so hard with no cure. My confidence [in managing my epilepsy] is contributed to by my parents and the SMART program. They showed that we are also human |

(*continued on next page*)

**Table 2** (*continued*)

| Thematic Category 1: Barriers to Epilepsy Self-Management |
|---|
| beings who are thought of. They also educated us about our illness, something that we didn't have before. |
| **4b4. Program Learnings:** *Participants sharing helpful learnings from the session content (*e.g., *information about seizures, stress management, sleep hygiene, improvements with nutrition) or from health providers.* |
| Week 24 |
| ETAU (n = 7): I was not used to drinking water or eating food at specific times. When I joined this program, the nurse told me to take plenty of water to control my disease. I also learned to eat food that is enough and healthy. |
| SMART (n = 7): I did not know that epilepsy had a treatment. Secondly, I did not know that one is born with epilepsy. I thought that maybe someone had spread it to me. After joining the SMART program, I was educated about it and also learned how to manage it. Thirdly, epilepsy is not an illness that is going to affect your way of life, especially if you are taking your medicine well. |

*Note*. SMART-U = **S**elf-**M**anagement intervention for **R**educing **T**he epilepsy burden among **U**gandans (SMART-U); ETAU = Enhanced treated as usual. MTN = mobile telephone number.

participants.

### 3.3. Current self-management behaviors and attitudes

#### 3.3.1. Epilepsy self-management behaviors

Participants across both intervention arms reported engaging in a range of self-management behaviors, including adherence to anti-seizure medication, sleep regulation, stress management, dietary adjustments, avoidance of seizure triggers, and attendance at clinic appointments. These behaviors were commonly endorsed at both Week 13 and Week 24.

However, SMART-U participants more frequently described specific, intentional self-management strategies, particularly related to stress management, anticipatory planning for seizures, and adherence routines. ETAU participants described similar behaviors but often emphasized medication use alone, with fewer references to broader lifestyle or problem-solving strategies.

#### 3.3.2. Attitudes and confidence related to self-management

Positive attitudes toward self-management, including increased confidence, independence, and sense of control, were reported by participants in both groups. These attitudes were more prominently and consistently endorsed among SMART-U participants at both timepoints. By Week 24, many SMART-U participants described feeling better equipped to manage epilepsy in daily life, whereas ETAU participants more often described continued reliance on healthcare providers to direct care decisions.

#### 3.3.3. Seeking support from others

Seeking support from family members, peers, healthcare providers, or community organizations was infrequently endorsed overall but showed notable differences by intervention arm. SMART-U participants more often described proactive engagement with peers, group facilitators, or healthcare providers, particularly following the intervention. ETAU participants described limited support-seeking and, in some cases, reluctance to disclose epilepsy-related concerns to others.

### 3.4. Facilitators of epilepsy self-management

#### 3.4.1. Social and family support

Support from family members and close social networks emerged as a key facilitator of self-management across both groups. This theme was consistently endorsed at both timepoints. SMART-U participants more frequently described improved family understanding and involvement in epilepsy care over time, whereas ETAU participants described more variable family support.

#### 3.4.2. Access-related and practical facilitators

Participants identified practical facilitators, including improved medication access, knowledge of epilepsy care pathways, and use of stress-management and adherence strategies, as supportive of self-management. These facilitators were more frequently and concretely described by SMART-U participants, particularly at Week 24, suggesting increased integration of learned skills into daily routines.

### 3.5. Participant perspectives on SMART-U and ETAU

#### 3.5.1. Perceived helpful aspects of the interventions

Participants in both groups identified helpful components of their assigned care. However, SMART-U participants overwhelmingly emphasized the value of intervention content, including group sessions, written materials, problem-solving strategies, and opportunities to learn from peer educators with lived experience of epilepsy.

Intervention support, particularly from peer educators, nurses, and group facilitators, was universally endorsed among SMART-U participants and described as fostering trust, understanding, and motivation. ETAU participants acknowledged receiving educational information but described fewer interpersonal or supportive elements of care.

Participants in the SMART-U group also described perceived benefits of participation, including improved understanding of epilepsy, increased confidence in managing seizures and stress, and enhanced ability to communicate with family members and healthcare providers.

#### 3.5.2. Areas for improvements

Some participants across both arms identified areas for improvement. SMART-U participants occasionally noted challenges related to session length, literacy demands of written materials, or mobile health components. ETAU participants more frequently described dissatisfaction related to limited communication, lack of follow-up, and constrained access to providers.

Participants in both groups suggested improvements focused on expanding program reach, strengthening communication with healthcare providers, addressing structural access barriers (e.g., transportation, medication supply), and increasing education for families and communities to reduce stigma.

### 3.6. Discussion

This qualitative study examined how participants in SMART-U versus ETAU experienced epilepsy self-management, stigma, and care, with the aim of 1) assessing intervention impact on patients and their families, 2) identifying key themes, and 3) informing future intervention development. Across both groups, participants described substantial structural and social barriers to effective epilepsy self-management, including limited access to care, financial constraints, and pervasive stigma. Despite these shared challenges, SMART-U participants consistently reported greater gains in confidence, problem-solving skills, and social support, suggesting that the intervention influenced both their care experiences and their broader approach to living with epilepsy.

Differences between SMART-U and ETAU participants were particularly evident in how individuals engaged in self-management. SMART-U participants more frequently described intentional, proactive strategies extending beyond medication adherence, including stress management, planning around seizure triggers, and adapting daily routines to reduce risk and improve functioning. In contrast, ETAU participants tended to characterize epilepsy management as primarily provider-driven, reflecting greater reliance on clinicians and reduced perceived personal control. These findings suggest that SMART-U's peer-led, skills-based approach may shift participants' understanding of their role in care, promoting greater engagement and self-efficacy in epilepsy self-management [17].

Stigma emerged as a pervasive and enduring challenge across both treatment groups, consistent with prior research in LMIC settings

demonstrating the substantial social and cultural burden of epilepsy [25–28]. Participants described social exclusion, fear of disclosure, and community misconceptions about epilepsy. However, SMART-U participants more frequently articulated strategies for coping with and responding to stigma, particularly within family and community contexts. They also demonstrated greater awareness of the impact of stigma on their daily lives. In contrast, ETAU participants more often described stigma as externally imposed and largely unavoidable, with fewer references to adaptive coping. These findings highlight the potential role of peer support and shared lived experience in facilitating more adaptive responses to stigma in culturally relevant ways [29].

Participants from both groups reported limited support from family members, friends, and employers, which was described as exacerbating isolation and complicating medication adherence and clinic attendance. This might be explained by the social cognitive theory which highlights the importance of supportive social relationships among people with epilepsy. Lack of supportive relationships from family members, friends and employers, makes it difficult to engage in heathy behaviors. This might also be explained by poor knowledge, negative attitudes and misconceptions about epilepsy [30,31].

Over time, differences in feedback between groups became more pronounced. From Week 13 to Week 24, SMART-U participants demonstrated clearer shifts toward increased self-efficacy, more intentional self-management behaviors, and a more reflective understanding of epilepsy and its impact on daily life. They also described improved communication with healthcare providers and greater confidence in managing ongoing challenges. In contrast, ETAU narratives remained relatively stable across time points, with limited evidence of change in attitudes, behaviors, or perceived control. These qualitative trajectories may help contextualize future quantitative findings from the parent trial, particularly with respect to seizure outcomes, quality of life, and psychosocial functioning.

These findings have important implications for epilepsy care in Uganda and similar settings. Peer-delivered self-management interventions appear to be a feasible and potentially impactful approach in contexts with limited access to specialist care. As demonstrated in the current study and reflected in other studies of individuals with various chronic health conditions, [32], including peer educators in study interventions may enhance engagement by providing culturally relevant guidance, modeling adaptive coping strategies, and fostering trust through shared lived experience. Additionally, the findings underscore the importance of addressing stigma, strengthening patient–provider communication, and enhancing social support as core components of epilepsy care. Interventions that extend beyond biomedical management to incorporate psychosocial and contextual factors may be critical for improving outcomes among people with epilepsy in LMICs [17].

This study has several strengths. Embedding qualitative interviews within an ongoing randomized controlled trial enabled a deeper understanding of participant experiences and potential mechanisms underlying intervention effects. The longitudinal design allowed for examination of changes over time, and inclusion of both intervention and control groups strengthened comparisons across care contexts. Moreover, collecting participant feedback during the intervention period may facilitate the incorporation of patient perspectives into future program refinement.

However, findings should be interpreted considering several limitations. The sample size, although appropriate for qualitative inquiry [33], was relatively small and may not capture the full range of experiences among people with epilepsy in Uganda. Data were based on self-report and may be subject to recall or social desirability bias. Despite efforts to ensure analytic rigor, findings may reflect researcher perspectives inherent to qualitative analysis. Additionally, because we did not assess whether participants had previously participated in epilepsy-related research studies or educational interventions at these clinic sites, prior research exposure may have influenced participants' knowledge, perceptions, or responses. Finally, structural barriers such as medication access and healthcare infrastructure were not directly addressed by the intervention and remained persistent challenges for participants.

## 4. Conclusion

SMART-U appears to influence not only what participants do to manage epilepsy, but also how they think about and live with their condition in daily life. Participants in the peer-led SMART-U intervention described greater confidence, more intentional and multifaceted self-management strategies, and an improved ability to navigate the social and structural challenges associated with epilepsy. Taken together, these findings suggest that peer-supported self-management may represent a feasible, culturally relevant, and meaningful adjunct to epilepsy care in LMICs, particularly in contexts where access to specialist care and resources is limited.

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## Declaration of generative AI use

No generative AI was used for this manuscript.

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