Self-management for people with poorly controlled epilepsy: Participants’ views of the UK Self-Management in Epilepsy (SMILE) program

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Abstract

Background: Epilepsy is a long term condition that requires self management, but currently, there is no well evaluated epilepsy self education or self management intervention in the United Kingdom (UK).

Aim: The aim of this study was to examine the views and experiences of the first participants of the Self Management in epilepsy UK (SMILE UK) program to assist the development of a full trial.

Method: In depth semistructured interviews and group discussions were conducted with 10 people with poorly controlled epilepsy to explore their views and experiences of the self management program. Interviews were audio recorded, transcribed, and analysed thematically.

Results: All participants viewed the program positively. Three themes emerged: i) peer support was experienced through knowledge sharing, disclosure of experiences, and exchange of contact details; ii) participants felt better equipped to enter discussions with doctors and other health care professionals about their condition; and iii) participants reported an improvement in their personal life through increased confidence to live with epilepsy and acceptance of their diagnosis.

Conclusion: A brief group self management intervention increased knowledge and confidence in managing epilepsy.

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1 Introduction

One of the greatest challenges to global health and social care organisations is the increasing prevalence of long term conditions and multiple morbidity [1]. The associated health care costs are considerable: estimates for the proportion of total national health expenditure in the United States associated with chronic disease is 75% [2]. In England, 80% of general practitioner consultations are by people with chronic disease [3]. The concern to both reduce costs and increase quality of life has led to an increased focus on self care strategies as a central component of the management of long term conditions with the aim of enhancing patients’ knowledge, skills, and confidence to manage their own health [4]. Variations exist in the literature for defining self management, but in its simplest form, it describes a patient taking an active role in his or her treatment [5].

Epilepsy is a long term condition that requires individuals to learn to manage their own condition, including identifying and managing seizure triggers, implementing strategies to comply with multiple antiepileptic drugs, implementing precautions to minimize seizure related risks, and educating others what to do during and following a seizure.

A consistent finding is that many people with epilepsy would like to refine better provision of information about how to live with and manage their condition [6]. However, currently, there is no well evaluated self education or self management intervention in the United Kingdom (UK) for epilepsy, despite this being a relatively common condition with over 600,000 people with epilepsy in the UK and estimates that countries in Europe spend around 1% of their national health care expenditure on epilepsy [11].

Cochrane reviews [12,13] have found four epilepsy specific educational interventions, including the Modular Service Package Epilepsy (MOSES) program, developed in Germany and offered as part of routine epilepsy care in the German health care system [14]. The MOSES program can be offered as a two day educational program for groups of between eight and 12 individuals, and relatives/carers may attend. It is suitable for application in both inpatient and outpatient settings for people with epilepsy aged 16 years and older without a learning
disability. The program is designed to foster interaction between those
attending as well as with the course leaders and to encourage process
ing of material at an emotional and cognitive level as well as facilitating
a change in behavior. The MOSES program has demonstrable benefits
including improved knowledge about epilepsy, better seizure control
and coping, and a greater tolerance of and fewer reported side effects
of antiepileptic drugs [14]. We contend that MOSES shows promise for
transfer to the UK setting [15].

In preparation for trialing MOSES in the UK, we took advantage
of developmental work [16] to adapt it to the UK setting and build
workforce capacity through the development of high quality program
facilitators. The materials and course content were finalized as the
Self Management in Epilepsy (SMILE) program in May 2013, com-
prising nine modules: living with epilepsy, people with epilepsy, basic
knowledge, diagnosis, treatment, self control, prognosis and personal
and social life, and networking. These topics are delivered using a range of
Teaching techniques that encourage group participation and are also
based around some factual information: the use of statement scales
(participants are each invited to identify where on a scale they view
themselves in response to a statement such as “Epilepsy makes me
feel lonely”), brainstorming by the group, the provision of ideas used
for mind mapping, and conveying some information via factual slides.
Prior to undertaking a randomized controlled trial of SMILE (UK) [15]
with patients with poorly controlled epilepsy, we carried out pilot
work including the qualitative exploration of pilot patients’ personal
views and experiences of the program. It is these views and experiences
of the first UK recipients of the program that we report here.

2. Method

2.1. SMILE (UK) program

Two pilot courses were delivered. A course comprised two days
each 09:30 to 17:00 scheduled as four main half day sessions with a
lunch break and two further breaks for refreshments per day. Staff
with expertise in aspects of epilepsy management were recruited by
LR to act as course Facilitators. Each pilot course was delivered by two
Facilitators who were an epilepsy nurse specialist (ENS) and an EEG
Technician. The venue was the education center of a large teaching hos-
pital that was familiar to the participants through their treatment and
adjacent to the emergency department. Each participant was given a
copy of the program workbook, with chapters corresponding to the
nine modules that formed part of SMILE (UK). Each chapter contained
some factual information that served to underpin the more interac-
tional nature of the delivered sessions, with dedicated spaces for participants
to write notes or complete exercises, as well as bullet point summaries
of each of the topics covered during the sessions.

2.2. Participants

Twenty two people were recruited to the pilot study through an ad
vertisement placed on the website and social media associated with
Epilepsy Action (March 2013-May 2013). Nine were lost to recruitment
(unable to contact, health reasons, work commitments). Thirteen adults
with a formal diagnosis of epilepsy, being prescribed antiepileptic medi-
cation, who had experienced more than one seizure in the previous 12
months participated in one of two pilot SMILE programs and, addi-
tional ly, were invited to give their views and experiences. Two participants did
not complete the course. One participant required emergency depart-
ment treatment for an injury sustained during a seizure and did not at
tend one afternoon session, and the second participant left an hour
early on one of the days due to seizure related tiredness. Three partici-
pants declined to participate in these interviews.

The views and experiences of 10 participants in the SMILE (UK) pro-
cram were collected pragmatically through group interviews with one
group of three participants and semistructured interviews with seven
participants, of which four were conducted face to face and two as tele-
phone interviews, in response to individual preference. One participant
responded via email. Individual interviews typically lasted between 20
and 30 min, and the group session took 60 min. All data collection oc-
curred within one month of completing the SMILE (UK) course.

2.3. Interview topic guide

A topic guide was developed by the research team in consultation
with colleagues at Epilepsy Action. The topic guide covered participants’
reasons for volunteering, views of the course materials and style of the
course, and perceived usefulness of the program (Table 1). AL conduc-
ted the interviews and was not involved in the implementation of the
pilot courses to minimize data contamination.

2.4. Data analysis

Interviews and discussions were audio recorded and transcribed
verbatim. Each transcript was checked and read in full by AL, with a
sample read by MM and LR, to gain an overall perspective of the data
and to allow for a comparison of interpretations, thereby enhancing re-
flexivity. The topic guide prompts were flexible, allowing for revision of
prompts during interviewing phase if necessary. The formal process of
data analysis began with reading the transcripts and making notes of
participants’ perceptions and explanations in the margins. Data were
analyzed iteratively, going back and forth between data and an emerg-
ing structure of “ground up” themes related to the study objectives.
The qualitative data analysis software NVivo 9 (QSR International) was used
to systematically code the data and assist analysis. Emerging findings
and interpretations were discussed during group meetings.

The National Research Ethics Committee London (Fulham) approved
the study (12/LO/1962). Informed consent was obtained from all
participants.

3. Findings

3.1. Participants’ characteristics

The participants’ mean age was 37 years (SD 13.1), mean years living
with epilepsy was 25 years (SD 17.5), and 60% were female (Table 2).

Table 1

<table>
<thead>
<tr>
<th>Topic guide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Following brief introduction and reappraisal of consent and questions about participants’ circumstances (age, living arrangements, educational achievement), they were asked about their views and experience of taking part in the pilot SMILE (UK) program. The main prompts (in italics) are given below:</td>
</tr>
</tbody>
</table>

- Why did you decide to take part in the SMILE pilot? (t1)  
- Have you been involved in anything like this before? (t1)  
- Was it because it was something you had been looking for already, or was it the idea of being part of something new in epilepsy treatment, for example? (t1)  
- What did you think of the content of material that was delivered during the two days? (t2)  
- Topics covered? Were any that were particularly useful? Any that you found didn’t particularly like? (t2)  
- How did you find the way in which information was delivered? Was it easy to understand or a bit difficult? (t2)  
- How did you find learning with others in a group? (t2)  
- Were there any advantages to this for you? Were there any disadvantages for you? (t2)  
- Did you find it easy to participate and contribute or was this difficult? (t2)  
- What did you think of the different teaching methods used? (Statements, mind maps, brainstorming and information slides) (t2)  
- Did you like the different teaching methods used during the course or did you find them confusing? (t2)  
- How useful do you consider the course to be in the future? (t2)  
- Do you think you’ll be able to use anything you experienced on SMILE again? Useful to use with others in your life? (t2)  

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The most frequent type of epilepsy self reported by participants was temporal lobe epilepsy. Only three participants were in formal employment, all on a full time basis. All participants had achieved GCSE level qualification at a secondary school, four had obtained an undergraduate degree, and one obtained a postgraduate degree.

3.2. Smile (UK): participants’ views

Participants reported a variety of reasons for volunteering to take part in the pilot SMILE program. For one, it was part of taking control of her life and fitted in with her self management decision making: for four participants, taking part was for general interest, in particular meeting others with epilepsy; two participants took part because the research was developing a new treatment, including one individual who saw it as “giving back” to the medical community.

Of the nine topics covered during the course, four were highlighted as being particularly useful: Basic Knowledge, a chapter which covers common questions about epilepsy, including the different causes of epilepsy, the development of seizures, and how to identify different types of seizures; Diagnosis, a chapter which covers the most important investigations for the diagnosis of epilepsy, including how to accurately observe and describe seizures and document them, and to assess correctly the risks of different investigations; Self control, a chapter which covers opportunities to influence how and when seizures occur, including avoiding seizure triggers and learning how to interrupt seizures; and Personal and Social Life, a chapter which covers the psychosocial aspects of epilepsy, including how to improve self esteem and supporting independent living. No topic was identified as being redundant. The main areas of criticism about the program were about duration and infrequent use of the workbook during classroom based activities: first, participants perceived the course to be intensive over two days and the preference would have been for the course to have been scheduled over three days; and second, participants would have appreciated greater reference to the program workbook by the Facilitators, including more encouragement for participants to write in it and make individualized notes.

When participants described their experiences more deeply, three themes began to emerge: the group experience, application of new knowledge, and personal life improvement.

3.2.1. Peer support

A key motivating factor in participating in the SMILE (UK) program was meeting others with epilepsy. This was especially demonstrated by the fact that during the second day for each pilot course, participants requested the exchange of personal details and a forum to be set up for them, e.g., Facebook page, email mailing list. Eight respondents saw other group members as having become experts in epilepsy through experience, thus, allowing their own personal knowledge to be increased about shared types of epilepsy. In particular, participants commented on the value of exchanging personal experiences of treatments for epilepsy, especially drugs and surgery. There was a feeling that decision making was improved by interacting with people who had already made a similar decision and who were living with that decision:

“I was very keen to meet other people with epilepsy and learn new information...it was really interesting to see a variety of perspectives based on personal experiences...[The group discussed]...different treatments they have experienced, and talk about how the drugs they have tried and share different views on how the drug worked for them differently...it was also good to speak to people who have had other treatments such as surgery or VNS” (participant 9).

“I have met with a doctor here about surgery and also it was good to meet somebody else [on the course] who has been through surgery and to be able to talk about it, how it made her feel” (participant 7).

The three participants who had been living with epilepsy for more than 34 years were able to share their knowledge about different situations and experiences, which was of particular importance for those with a recent diagnosis of epilepsy who were just starting on the journey of acceptance:

“I’ve caught up with being alright like they’re just starting off with square one, down on the bottom” (participant 5).

Participant 6 corroborated this by describing the different stages of a process of having epilepsy. She placed it in the context that she had been living with epilepsy since she was seven years old, yet someone else in the group had only been diagnosed at the age of 20, which was very recent:

“So we’re all in a different stage of the epilepsy process and it’s learning to live with epilepsy, the initial shock, finding a voice, positive steps about epilepsy. Some of these other people might just be at an initial staged, still in shock, still processing the fact that they have epilepsy and so to put people with their experiences in the course, we could influence from our experiences” (participant 6).

It was acknowledged that as they were all in the same situation of having epilepsy, this made the group situation much easier:

“Normally, I’d be a bit self conscious about these groups but once I got used to it, knowing that everyone’s like, the same, as me and there’s like a big understanding amongst the group and become friends and stuff, it was actually pretty good” (participant 2).

However, a barrier to a successful group setting sometimes arose through “one upmanship”, a dominant individual, or nervousness.

Table 2

Demographics of people with epilepsy participating in SMILE (UK) pilot.

<table>
<thead>
<tr>
<th>ID</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Years with epilepsy</th>
<th>Type of epilepsy (self-report)</th>
<th>Education</th>
<th>In employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>33</td>
<td>13</td>
<td>Occipital lobe</td>
<td>Postgraduate</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>21</td>
<td>21</td>
<td>Temporal lobe</td>
<td>Secondary school</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>48</td>
<td>47</td>
<td>Complex partial</td>
<td>Secondary school</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>60</td>
<td>44</td>
<td>Temporal lobe</td>
<td>Undergraduate</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>53</td>
<td>52</td>
<td>Frontal lobe</td>
<td>Secondary school</td>
<td>Yes</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>40</td>
<td>34</td>
<td>Complex partial</td>
<td>Undergraduate</td>
<td>No</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>32</td>
<td>9</td>
<td>Frontal lobe</td>
<td>Secondary school</td>
<td>Yes</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>32</td>
<td>8</td>
<td>Temporal lobe</td>
<td>Undergraduate</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>F</td>
<td>21</td>
<td>15</td>
<td>Complex partial</td>
<td>Secondary school</td>
<td>No</td>
</tr>
<tr>
<td>10</td>
<td>F</td>
<td>29</td>
<td>8</td>
<td>Temporal lobe</td>
<td>Undergraduate</td>
<td>Yes</td>
</tr>
</tbody>
</table>
about participating in front of strangers. One respondent also noted how the extreme positive experiences could sometimes impact negatively on others in the group:

“Because you were very positive about your epilepsy and that dinned somebody at the end. They were dinned with you about being so positive” (participant 6).

She also reflected on the potential problem of one-upmanship and although she had not experienced it in her group, she explained that she had kept quiet deliberately for some of the course to avoid this. As she explained:

“Sometimes people with epilepsy have to go one worse than the person next to them. In some sort of perversely, it turns out to be a competition for who...who’s worse and who’s undergone the worst experience...” (participant 6).

Finally, it was noted by participant 3 that the danger of a group setting was that an individual could dominate discussions and cause difficulties within the group:

“Some of the topics [in the programme] weren’t touch because individuals dominated the group and so the discussion went off on a side track... so I think being aware of one individual not being able to dominate the whole thing” (participant 3).

3.2.2. Applying new knowledge and learning

This was facilitated through the course workbook, which was considered by all to be essential as a reference resource for the future and a way of making the content portable for them as well as allowing others access the new information:

“It lives kind of by my bed...everything I want is in one place, which is nice... My Mum loved the book, because obviously she can read it as well” (participant 10).

“I can’t stop carrying it around. Before I used to carry around my iPad all the time and bring that out all the time. But this is what I have to read all the time” (participant 7).

Two types of explanation emerged of how participants would apply their new learning. One related to being able to offer more to a doctor or nurse during clinic appointments through more detailed answers, which they felt would then produce better answers from the health professional. As participant 2 explained:

“When I see epilepsy nurses and neurologist and consultants in the future, instead of just hopeing to give them small answers...you can give them more detailed and structured answers. And you'll probably get a better sort of answer out of the person you're speaking to.” (participant 2).

Similarly, participant 4 saw her increased knowledge as empowering and put her on a level footing with her doctor:

“It’s empowering you when you got to see the doctor to be more two way about the discussion” (participant 4).

Participant 3 also spoke of being more informed and able to talk and have an opinion about a course of treatment:

“It’s armed me with more information and sort of questions that I can ask and talk to other people...it’s encouraging to go and ask questions rather than just being told and saying to your doctor well have you thought of doing this, can I do this or can I try this new medication? Rather than just relying on the doctors. It’s inspired me in that respect to question and not actually just to accept what the doctor says” (participant 3).

For another participant (participant 7), it was a way to help a general practitioner understand her condition. She described a “blind leading the blind” relationship with her GP, and her increased SMILE (UK) knowledge would help them both through discussions about her epilepsy and strengthen their relationship:

“I think it will [be useful for interacting with health professionals]. With my GP as well...because I don’t feel my GP, I don’t think he knows...I think he feels I don’t know enough about epilepsy and I don’t feel he knows enough either so we’re both in the same boat in a way so just to talk to him, so during my appointments with him, talk to him about it” (participant 7).

The second response to the learning and understanding gained through SMILE (UK) was through the education of family members. Some described their relatives as benefiting from the workbook, while the husband of one participant accompanied her to the hospital for the course and stayed for the first day because he felt that he also had a need to increase his knowledge and understanding. The same participant’s family believed that her epilepsy was caused by evil spirits and she appreciated having information she could share with them to educate them better:

“And it was also good for my partner [attended day 1]. He actually, because he said he needed to learn a bit more” (participant 7).

“With my family. Like, to inform them more about it. Because a lot of them feel like, around the religion part, because they feel it’s the evil spirits but they need to know a bit more about it” (participant 7).

3.2.3. Improving the person’s personal life

Some participants described the SMILE (UK) training as leading to an improvement in their life through increasing their acceptance of the diagnosis:

“Because I know a bit more and before [the course] it was actually having acceptance of epilepsy [that was a problem]. I would say I’m, by percentage, I’m like on 80% now...and it was meeting other people as well and being able to talk about it” (participant 7).

Three participants spoke of their increased confidence following their interaction with others with epilepsy, with one participant feeling “proud”, suggesting the potential for a protective effect against perceived stigma.

“I came away from this course feeling more confident and proud” (participant 9).

“Oh the confidence to talk, yeah. Because it has given me more, more confidence, because I know a little bit more...and it was meeting other people as well and being able to talk about it” (participant 7).

“I think you’ve probably re stimulated me to organise my life! I don’t know that I will but at least had that effect” (participant 4).

One participant seemed to suggest that through the discussions with peers and guidance by the pilot course leader, he began to reflect on his...
personal coping mechanisms and that perhaps, he judges himself too
harshly in his day to day life:

“It does make you think though, maybe I’m, you know, I’m too mis-
erable, am I a bit harsh with myself?” (participant 8).

4. Discussion

Epilepsy is a common long term condition requiring a high level of
daily self management, yet no self management programmes have yet been
tested in the UK. We present here the experiences and views of the first
UK patients with epilepsy to participate in a pilot of a self management
program, SMILE (UK), prior to a formal randomized controlled trial
[15,17]. Broadly speaking, participants enjoyed the program and the asso-
ciated manual, supporting previous work that found universal popularity
for a self management intervention [18] and the generally positive re-
sponses to MOSES in Germany [14]. Importantly, three key findings
emerged about program experiences: first, participants described power-
ful peer support during the program, experienced through the sharing of
knowledge, disclosure of experiences, and exchange of contact details
between peers independently of the program; second, participants felt
better equipped to enter discussions with doctors and other health care
professionals about their condition following the program; and finally,
participants experienced an improvement in their personal life through
increased confidence to live with epilepsy and acceptance of their
diagnosis.

The finding that the group setting and peer support through the
SMILE (UK) program was perceived to be a positive experience echoes
other self management studies [19–24]. For example, Skinner et al.
[20] demonstrated that interaction between participants during a self
management program for diabetes mellitus changed their illness percep-
tion, with the less facilitators talked (and thus, the more group partici-
pants interact) having a positive effect on change in illness perception.
An explanation of the effect of peer support may be found in Social
Learning Theory; a Cochrane review [25] of lay educator delivered self
management programs for people with chronic disease considered
peers to be role models, based on the modeling construct in Bandura’s
Social Learning Theory [26]. This construct indicates that learning
through the observation of others is a particularly important influence
on behavior and there needs to be a quality that is desirable to be imitat-
ed. Thus, someone dealing particularly well with their epilepsy was a po-
tential role model to others in the group; this opportunity for learning
would not have come about through didactic learning styles or indeed
from health professionals’ expertise. Indeed, to illustrate this, partici-
pants spoke strongly of the benefit of meeting someone with epilepsy
who had made the decision to undertake a surgical treatment about
which they had been grappling to make a decision. Patients can see
how others manage their disease, learning from their experiences, and
thus, work to improve their own health status [27]. Particular aspects
of the program delivery facilitated the peer support findings reported
here: for example, the timetable for the program included three sched-
uled breaks per day, meaning participants could informally interact
with individuals from whom they wanted to gather specific or intimate
information. Facilitators also could offer more tailored advice during
these breaks. The teaching methods also facilitated role modeling, with
participants being invited to enact situations personally experienced,
for example, being found post-seizure.

The aim of self management approaches was to have well inform-
ated patients, who are able to make effective decisions and choices them-
selves about their long term condition; this is referred to as increased
health literacy [28]. Definitions of health literacy initially mostly cen-
tered on the patient’s ability to understand health information, although
recent conceptualizations include the influences of social determinants
such as peer groups, mass media, and culture [29]. Low health literacy is
related to poor self management [30], low involvement in consultations
with health professionals and decision making [31], higher emergency
department use [32], and increased hospitalization [33]. Health literacy
seems to focus on knowledge, but perhaps, what is also important and
gained from self management groups is confidence, self esteem, and
practical guidance. Certainly, our pilot findings suggest that there is an
effect of empowerment for these participants that might enable more
equal engagement with health professionals. The teaching methods
employed by the program encourage participation and build up during
the day, from speaking in pairs to participants standing in front of the
group to indicate on a diagram their personal feelings about their condi-
tion, e.g., a response to the statement “epilepsy makes me feel sad”. The
building up of methods develops the confidence of participants to con-
tribute to the group and to learn to communicate their experiences or
feelings. Furthermore, the program offers sustained interaction with
specialist health professionals, where some individuals may only see
an epilepsy specialist annually, depending on their health service provi-
sion. Having the program facilitated by experienced epilepsy practi-
tioners gives participants the opportunity to develop strategies to
communicate with potentially unfamiliar health professionals.

Finally, the benefits of collecting qualitative data during a trial are
considerable. At this pilot stage, it was possible to further develop the
skills of newly trained facilitators by, for example, disseminating partici-
patant responses about the perceived competitiveness within the groups
that might be present among people living with epilepsy, advising how
to deal with the problems posed by a dominant member of a group, and
training facilitators to refer more explicitly to the workbook, encour-
aging participants to annotate their workbook to tailor it and build per-
sonally salient knowledge. By including qualitative methods at the pilot
stage, the nested qualitative study for the main trial has been strength-
ened through reflecting on important areas to include in future inter-
view schedules.

4.1. Limitations of the study

First, this is a small study of self selected volunteers from an
epilepsy specific charity (Epilepsy Action), and the sample may have in-
cluded highly motivated and interested people with epilepsy, for whom
learning more about their condition was particularly important. Such
self selection is a general feature of participation in self management
programs [25]. Second, we report here the first patients receiving this
intervention from health care professionals newly trained to deliver
SMILE (UK), and it is possible that the course leaders’ ability to deliver
the intervention will increase with greater experience, thus, enhancing
the benefits of SMILE (UK). In addition, we acknowledge that data were
collected by different means and that in particular, group interviews
might have inhibited participants’ comments. However, it was felt that
any effects of group interviews (e.g., not wanting to answer in front of
others, reveal true feelings) would be limited through the fact that the
interview groups were made up of participants who had attended the
same pilot course together and there was already a sense of familiarity
among the two pilot courses given rise to different views by participants.

5. Conclusions

Qualitative findings from modest pilot work suggest that people
with poorly controlled epilepsy experience important peer support
and increased self efficacy effects from the first UK delivery of the
Self Management in epilepsy (SMILE) program.

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