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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 analyzed 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.

1. Introduction

One of the greatest challenges to global health and social care organizations 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 receive better provision of information about how to live with and manage their condition [6–10]. 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

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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 processing 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-Ma*nagement in ep*ILE*psy (SMILE (UK)) program in May 2013, comprising nine modules: Living with Epilepsy, People with Epilepsy, Basic Knowledge, Diagnosis, Treatment, Self-control, Prognosis, 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 hospital 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 interactional 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 advertisement 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 medication, and who had experienced more than one seizure in the previous 12 months participated in one of two pilot SMILE programs and, additionally, were invited to give their views and experiences. Two participants did not complete the course. One participant required emergency department treatment for an injury sustained during a seizure and did not attend one afternoon session, and the second participant left an hour

early on one of the days due to seizure-related tiredness. Three participants declined to participate in these interviews.

The views and experiences of 10 participants in the SMILE (UK) program 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 telephone interviews, in response to individual preference. One individual responded via email. Individual interviews typically lasted between 20 and 30 min, and the group session took 60 min. All data collection occurred 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 conducted 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 reflexivity. The topic guide prompts were flexible, allowing for revision of prompts during the 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 emerging 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.

Table 1
Topic guide.

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:

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

Table 2
Demographics of people with epilepsy participating in SMILE (UK) pilot.

ID	Gender	Age (years)	Years with epilepsy	Type of epilepsy (self-report)	Education	In employment
1	F	33	13	Occipital lobe	Postgraduate	No
2	M	21	21	Temporal lobe	Secondary school	No
3	M	48	47	Complex partial	Secondary school	No
4	F	60	44	Temporal lobe	Undergraduate	No
5	M	53	52	Frontal lobe	Secondary school	Yes
6	F	40	34	Complex partial	Undergraduate	No
7	F	32	9	Complex partial	Secondary school	Yes
8	M	32	8	Frontal lobe	Undergraduate	No
9	F	21	15	Complex partial	Secondary school	No
10	F	29	8	Temporal lobe	Undergraduate	Yes

3. Results

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). 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 this 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 stage, 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

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 narked somebody at the end. They were narked 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 perverse way, 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 (sic) 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 to 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 hoping 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 having 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 it 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 miserable, 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 program has to date 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 associated manual, supporting previous work that found universal popularity for a self-management intervention [18] and the generally positive responses to MOSES in Germany [14]. Importantly, three key findings emerged about program experiences: first, participants described powerful 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 perception, with the less facilitators talked (and thus, the more group participants interacted) 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 imitated. Thus, someone dealing particularly well with their epilepsy was a potential role model to others in the group; this opportunity for learning would not have come about through didactic learning styles or from health professionals' expertise. Indeed, to illustrate this, participants 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 scheduled breaks per day, meaning participants could interact informally 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, e.g., being found postseizure.

The aim of self-management approaches is to have well-informed patients, who are able to make effective decisions and choices themselves about their long-term condition; this is referred to as increased health literacy [28]. Definitions of health literacy initially mostly centered 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 condition, e.g., a response to the statement "epilepsy makes me feel lonely". The building up of methods develops the confidence of participants to contribute 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 provision. Having the program facilitated by experienced epilepsy practitioners 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 participant 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 instructing Facilitators to refer more explicitly to the workbook, encouraging participants to annotate their workbook to tailor it and build personally salient knowledge. By including qualitative methods at the pilot stage, the nested qualitative study for the main trial has been strengthened through reflecting on important areas to include in future interview schedules.

4.1. Limitations of the study

First, this was a small study of self-selected volunteers from an epilepsy-specific charity (Epilepsy Action), and the sample may have included 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 and trust between them. We did not, given the small sample size and the different means of data collection employed, seek to explore whether the two pilot courses gave rise to different views by participants.

5. Conclusions

Qualitative findings from modest pilot work suggest that people with poorly controlled epilepsy experienced important peer support and increased self-efficacy effects from the first UK delivery of the *Self-M*anagement in ep*ILE*psy (SMILE) program.

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Disclosure

The authors have no conflict of interest to declare.

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