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# People with epilepsy obtain added value from education in groups: results of a qualitative study

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epilepsy, experiential learning, patient education, self-management, social stigma, social support

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**Background and purpose:** Having epilepsy requires individuals to learn about self-management. So far, trials of self-management courses have not included in-depth qualitative evaluations of how the learning method influences participants' perceptions and behaviour. We aimed to interview participants who had attended a course, as part of a randomized controlled trial, to examine: (i) their perceptions of what they valued and negative aspects of the intervention, and (ii) whether and in what ways they continued to make use of the training.

**Methods:** Twenty participants were selected within 6 months of undertaking a course from the larger randomized controlled trial conducted in England. Semi-structured interviews were based on a topic guide.

**Results:** Participants' characteristics were representative of the clinical and demographic characteristics of the trial group. Their mean age was 44 years, half were male, and three-quarters had had epilepsy for over 10 years and had experienced one or more seizures in the previous month. Participants valued the opportunity to meet 'people like them'. Structured learning methods encouraged them to share and compare feelings and experience. Specific benefits included: overcoming the sense of 'being alone' and improving self-acceptance through meeting people with similar experience. Over half reported that this, and comparison of attitudes and experience, helped them to improve their confidence to talk openly, and make changes in health behaviours.

**Conclusions:** People feel socially isolated in long-term poorly controlled epilepsy. They gain confidence and self-acceptance from interactive groups. Expert-facilitated courses that encourage experiential learning can help people learn from each other, and this may enhance self-efficacy and behaviour change.

## Introduction

Epilepsy is similar to type 1 diabetes in being a long-term condition that is episodically difficult to control, resulting in medical emergencies and risk of premature death [1–3], but epilepsy is twice as common [2,3]. Clinicians provide a diagnosis, and advice on

medication, but day-to-day management requires attention to lifestyle, which must be undertaken by individuals themselves. People with epilepsy (PWE) would like more information [4]. However, self-management is influenced by personal and social attitudes [5], as well as being a cognitive process. Courses have been tested in long-term conditions, such as diabetes [6], and they are publicly funded in the UK [7]. Group courses have been evaluated for adults with epilepsy in some countries [8–10], and they are publicly funded in Germany.

In the UK, the advice given by Epilepsy Nurse Specialists to individual PWE has been evaluated [11],

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but group courses have not. Group interaction may provide additional benefits in reducing social isolation and increasing confidence [12,13]. PWE tend not to disclose their condition, which is linked to their perception of stigma [12,13], and this can lead to them being socially isolated [12,13]. Isolation and loss of confidence may further undermine their ability to manage their lives [14,15]. This has economic as well as social implications. PWE who perceive their condition as being stigmatized are more likely to attend and reattend Emergency Departments for seizures [1]. For every one planned hospital admission for epilepsy, six are unplanned via Emergency Departments [16], some of which might be avoided with better ambulatory services [17]. Therefore, providing support that improves self-confidence may be cost-saving [5,18,19].

In this context, we are undertaking a trial of self-management education in groups focusing on people with 'poorly controlled epilepsy', defined as having two or more seizures in the past year while on medication [20,21]. This group makes up approximately 40% of PWE [22].

In chronic conditions for which there is an evidence base, the relationship between providing education and achieving change in self-management remains largely unexplained both in terms of theory and evidence [23]. Qualitative studies are therefore recommended as an essential component of the evaluation of non-pharmacological, so-called 'complex' interventions with the aim of supplementing quantitative measures. They help to explain why and how an intervention 'works', or fails to do so, from the perspective of participants, thus contributing to the design and wider implementation of healthcare interventions [24–26]. The present study therefore aimed to provide an in-depth account of: (i) participants' perceptions of what they valued and any negative aspects of the intervention and (ii) whether and in what ways participants continued to make use of the training received.

### The intervention

We adapted the German Modular Service Package Epilepsy (MOSES) course for English speakers [8,20,21] to form the basis of the UK course called 'Self-Management education for adults with poorly controlled epILEpsy' [SMILE (UK)]. The course is purposefully interactive, recognizing that knowledge is necessary but not sufficient for behavioural change [23]. Therefore, it aims to promote participants as 'experts' and to enable them to gain self-confidence [8]. The course includes a facilitator's manual and a participant's manual handed out at the start of the

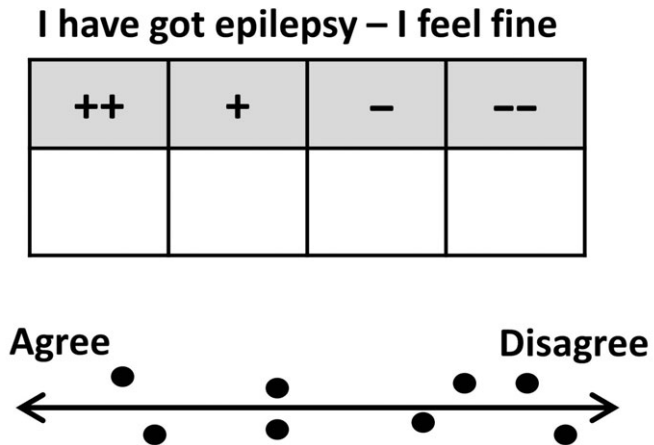
course. The nine chapters in the manuals match the nine modules in the course (Table 1). The UK course facilitators were Nurse Specialists and electroencephalography technicians who were trained by the German developers of MOSES. The courses ran on two consecutive days at an education centre adjacent to a hospital. Two facilitators ran groups with 6–12 participants, and learning was interactive, with feelings and self-esteem discussed, as well as facts about the prevalence of epilepsy, triggers, structured diaries and medication management. Participants began most modules by putting stickers on a flip-chart, representing their position on a spectrum of feelings, attitudes and behaviours (Fig. 1). Facilitators then encouraged participants to ask questions, and to share and compare their experience and coping strategies. The feasibility and acceptability of the course in the UK was initially tested in an external pilot with members of a national user group as volunteers [27].

**Table 1** Course modules

Title	Description of contents
1. Living with epilepsy	How to recognize and express different emotions that you may experience because of epilepsy How to develop better ways to cope with epilepsy
2. PWE	How common is epilepsy in the UK? When are you most likely to develop epilepsy? Famous PWE and what they have achieved
3. Basic knowledge	The causes of epileptic seizures, how seizures can develop and how to identify different seizure types
4. Diagnosis	How to observe and describe seizures accurately How to document seizures and the results of investigations
5. Treatment	Understanding different diagnostic methods An overview of the most common AEDs and different treatment options
6. Self-control	How to actively participate in your treatment How to avoid seizure triggers and be aware of auras/warnings Working out what might be relevant to developing methods of self-control
7. Prognosis	The chances of achieving seizure freedom and staying seizure-free after stopping AEDs Options if seizure freedom is not achieved
8. Personal and social life	How to improve self-esteem and social contacts Support for independent living, sports and professional life Driving regulations for PWE How to explain epilepsy to others
9. Network epilepsy	Addresses and other information related to treatment, psychosocial support and information specific for your epilepsy

AED, antiepileptic drug; PWE, people with epilepsy.

- Course is designed to be interactive
- E.g. How do you feel about this statement?
- Place a sticker on the scale



**Figure 1** Self-Management education for adults with poorly controlled epILEpsy (SMILE UK) facilitator techniques.

## Methods

The study was approved by the NRES Committee London – Fulham (reference number 12/LO/1962; Current Controlled Trials: ISRCTN57937389). Informed consent was obtained from all study participants.

### Inclusion/exclusion criteria and recruitment

Inclusion criteria for the randomized controlled trial (RCT), and thus for participants in this nested qualitative study, were: adults aged  $\geq 16$  years, having a documented diagnosis of epilepsy, currently prescribed antiepilepsy drugs, having reported  $\geq 2$  seizures in the previous year and able to provide informed consent, participate in workshops and complete questionnaires in English. Exclusion criteria were actual/suspected psychogenic, non-epileptic seizures only, active symptomatic seizures related to acute neurological illness or substance misuse, severe psychiatric disorder (e.g. psychosis), terminal cancer or being enrolled in other epilepsy-related non-pharmacological treatment studies. Epilepsy specialists invited patients attending clinics in the previous year.

### Nested qualitative methods

Participants were purposely selected from the 404 RCT participants to represent differences in gender, age, ethnicity and frequency of seizures as recorded prior to the intervention (L. Ridsdale, G. Wojewodka,

E. Robinson, et al, Submitted). Interviews took place at locations that were mutually agreed between the researchers and participants, including public places, such as cafés, as well as participants' homes. Topics had been generated with service users and the topic guide was piloted (Table 2). Topics included views of participants taking part in the courses, their perceptions of things they valued and found of particular benefit and any negative aspects as well as any factors that encouraged or hindered their participation, and whether and in what ways they had continued to make use of the training.

### Analysis

The interviews were audio-recorded and transcribed. The analysis proceeded alongside data collection and was based on a framework approach [28]. This is suitable for small numbers of cases and ensures that each case is fully taken into account in the analysis. This analytic approach requires identification of initial themes that are then grouped into a main theme and subthemes. This is applied to the raw transcript data for each interview. A thematic 'chart' is then created that summarizes information for each theme, which allows cross-case and within-case analysis through a process of constant comparison, with particular attention paid to deviant cases. Two members of the research team participated in all data analysis to reduce bias in the identification and interpretation of themes and categories.

**Table 2** Topic guide

Experience of epilepsy
Can you tell me a bit about <i>your</i> epilepsy?
Probes: seizure frequency, type
When did you find out you had epilepsy?
How did you feel when you were first diagnosed? How do you feel about it now?
How do you feel you cope with your epilepsy day-to-day?
Probes: employment, relationship anxiety
Help seeking
In the past, have you tried to find out more about your epilepsy?
How have you done this?
Probes: nurses, clinicians, support groups, internet, alternative therapies
SMILE course
When you first heard about SMILE, how did you feel about coming on the course?
Prompt: some people may feel worried or anxious before coming on a course like this, is this something that you experienced?
Probes: any worries about going on the course? Looking forward to it?
So, thinking about the SMILE course, what was the most interesting part of the course for you?
How did you feel about being part of a group?
How did you feel about hearing other people's stories?
How did you feel about discussing your emotions in the group?
During the course you were asked to place stickers on a line to describe how you felt about certain topics, how did you feel about doing this?
I believe there was some discussion about medication for epilepsy, was this useful?
Did you find out any things that were helpful?
Did you learn anything new about your epilepsy?
Probes: types of seizures, triggers, diagnostic techniques, other people's experiences
Since completing the course, do you think differently about your own epilepsy?
Probes: triggers, medication management
Impact of the course
Do you think the SMILE course has helped you in managing your epilepsy?
Probes: medication, triggers, warning signs, involvement in treatment
Have you used any of the techniques you learned on the course?
Although the workbook is not an essential part of the course, have you found it useful?
Have you stayed in touch with anyone from the course?
Probes: how many people? Have you found this useful?
Views about the course
Would you recommend other people with epilepsy to go on the SMILE course?
Is there anything about the course that you would like to change?
Is there anything else you would like to say about the SMILE course that you have not said so far?

SMILE, Self-Management education for adults with poorly controlled epILEpsy.

## Results

Of 24 participants approached within 6 months of course participation, 20 were interviewed. Two were

unable to attend for interview and two could not remember the course at all. Participants' mean age was 44 years, 10 were men and 17 were White. They had received an epilepsy diagnosis a median of 20 years previously and 15 had  $\geq 10$  seizures in the previous year (Table 3).

### Perceived benefits

#### *Overcoming a sense of isolation*

Thirteen participants described the benefit of meeting other people with experience of epilepsy, and explained that they had previously felt 'alone'. A typical comment was:

"Nobody without epilepsy can really understand what it's like to have a seizure... To see how they [other course members] deal with it makes it more easy to live with your illness because you think I am not alone" (male, 39 years).

Participants also spoke positively about learning about the frequency of epilepsy:

"I learnt about the amount of people that suffered from epilepsy in the UK and in London, and the famous people that apparently suffer from it" (male, 41 years).

#### *Being able to ask questions, share stories, feelings and experience*

Another advantage described by 13 participants was the learning method used by course facilitators, as this allowed participants to ask questions, share their stories and open up about their negative feelings. One said:

"(...) it was not a sort of 'sit down, shut up, and they carry on with a lecture' sort of thing, we could ask questions" (female, 51 years).

Another added:

"I felt that I wanted to discuss my story... When I said it out loud, it was a way of admitting how bad I have been over the years" (female, 54 years).

For some this resulted in them looking at their epilepsy differently:

"I felt like I was the only one dealing with it really, and it was getting me down... But when I heard that other people have got it, and I met the other people who have got it, I kind of changed my mind... I look at it in a different way" (male, 47 years).

This led to some becoming more comfortable and confident. One said:



**Table 3** Demographic and socioeconomic data of people with epilepsy who were interviewed

No.	Age (years)	Sex	Ethnicity	Highest qualification	Employment status	Living arrangements	Length of time since diagnosis (years)	Seizure frequency in last 12 months [25]
1	32	F	Other Black African/Caribbean	A Level	Unemployed	Lives alone	10	4-5
2	81	F	White	G.C.S.E.	Retired (due to age)	Lives alone	24	≥10
3	46	M	Mixed White and Black Caribbean	G.C.S.E.	Unemployed	Lives alone	19	4-5
4	50	M	Mixed White and Black Caribbean	None	Unemployed (due to health)	Lives with others	20	≥10
5	41	M	White	B.Sc.	Unemployed	Lives with others	29	≥10
6	38	M	White	Diploma	Self-employed	Lives with others	4	≥10
7	36	F	White	NVQ Level 3	Unemployed (due to physical disability)	Lives with others	35	≥10
8	59	M	White	None	Unemployed (due to health)	Lives with others	3	≥10
9	52	F	White	None	Unemployed	Lives with others	49	≥10
10	65	F	White	Diploma	Retired (due to health)	Lives alone	46	≥10
11	55	M	White	None	Unemployed (due to health)	Lives with others	2	≥10
12	54	F	White	G.C.S.E.	Unemployed	Lives with others	33	≥10
13	27	F	White	G.C.S.E.	Employed (part-time)	Lives with others	16	≥10
14	51	F	White	G.C.S.E.	Unemployed	Lives with others	40	1-3
15	39	M	White	B.Sc.	Employed	Lives alone	13	≥10
16	22	F	White	A Level	Unemployed	Lives with others	6	1-3
17	38	M	White	B Tech	Employed	Lives with others	10	1-3
18	54	F	White	Diploma	Unemployed	Lives with others	43	≥10
19	38	M	White	A level	Employed	Lives alone	6	≥10
20	58	M	White	B.Sc.	Employed	Lives with others	36	≥10

“I am a bit more comfortable now from just talking about it with a class full of other people who are going through similar types of experience” (male, 58 years).

Participants also developed their own ability and confidence as they contributed to others in the group:

“(…) to give advice to whoever is still in the confused world of ‘Oh why me, I don’t deserve epilepsy’… They gave us a chance to kind of help” (female, 32 years).

#### *Comparing different attitudes and experience*

Course facilitators asked questions about participants’ attitudes and practice during each module, and participants indicated their position by placing stickers on a board (Fig. 1). This identified a spectrum of responses that gave the opportunity for discussion about variations in views and experiences within the group. Thirteen participants reported that the process of comparing similarities and differences was helpful. Some were more reassured by becoming aware that others were coping with greater problems:

“Once you realize there’s people there that are a hell of a lot worse off than you and have got a lot bigger problems. That’s really selfish, but it sort of makes

you say well, actually, do you know what? It’s what a lot of other people deal with, you know” (male, 38 years).

Participants were quick to add that they were not glad that anyone suffered more than them, but it did make them feel like their situation was not so bad, and this was seen as a positive. One said:

“So in a way I’m lucky. I have to look at other people that are worse, because it makes me feel better… I thought people had it less than me. I didn’t know people had it more frequently. I thought I was the one that had it the worst, the most frequent, and I was thinking negatively about it… I feel better about it now, not so sad” (female, 52 years).

Another participant described a process of internal change:

“When you place a sticker on the line I think you start touching the person’s feelings… it pushes you back to yourself. And you come out thinking yeah… It can reverse a person from the inside” (female, 32 years).

#### *Comparisons triggering change in self-management*

All of the participants were seeing epilepsy specialists, but their contact was mainly restricted to drug

management. Following the course, 12 participants reported managing themselves differently, nine reported that they recognized triggers and warning signs better, so as to reduce their risks, four cut down on alcohol intake, and two learned not to fill the bath too high and to make sure that someone else was around when taking a bath. Five participants reported improved record keeping of their seizures and five improved their medication adherence, some using aids:

“I’ve picked a few tips up by listening to other people. I’ve got a box, you know, one of those boxes with the Monday, Tuesday, Wednesday on it... I actually got it after the course. Somebody was talking about it... The programme has helped me to understand more about epilepsy and medication. I take my treatment more seriously now” (male, 39 years).

#### *Becoming more open outside the group*

Almost half (eight) said that having the opportunity to compare their experiences of living with epilepsy within the group enabled them to be more open and talk more freely about epilepsy later on.

“I have never talked about epilepsy to anybody other than the doctor. I’ve never really had a general conversation about it... I suppose I am a bit more comfortable with it now through just talking with a class full of other people who are going through similar types of experiences” (male, 58 years).

Nine participants had read the workbook during and/or after the course, and four of these had lent it or photocopied pages for family or friends. Sharing knowledge of epilepsy with others helped them to feel like ‘experts’. A few said they felt more open with their neurologist and empowered in decision-taking on their medication.

Nineteen participants said that they would recommend the course to others, with a few adding it would also be particularly useful for those with newly diagnosed epilepsy or for people younger than themselves.

#### **Limitations of a group course and potential future improvements**

Despite entry criteria designed to exclude those whose language or learning abilities were insufficient, three participants reported that they frequently did not have the ability or English language skills to fully understand what was said and/or the group exercises, four reported memory challenges that made them forget parts of the course and/or forget to do things in real life, and two were not interviewed because they could not remember the course. Thus, nine out of 22 people

approached for interviews (about 40%) experienced language or memory problems, which limited the impact of the group course. Five found the course either started too early or went on too long. Suggestions included breaking down the 2-day course into shorter sessions and/or running it over 3 days, although not everyone agreed with this. Another suggestion was that the course should be offered to people younger than themselves or those with new-onset epilepsy.

## **Discussion**

We recruited participants attending epilepsy clinics who responded to the doctor’s invitation to a trial of a structured, expert-led course, facilitated in groups. The characteristics of the nested group were similar to the participants recruited to the trial at baseline in relation to age, gender, ethnicity, time since diagnosis and seizure frequency (Table 3). Participants valued the course particularly for helping them overcome a sense of isolation by meeting other people like themselves. Interactive learning methods enabled them to discuss their mostly negative feelings, and compare their attitudes and practice in a room with other people with experience of epilepsy. Many participants reassessed and changed specific aspects of their self-management.

#### **Strengths and weaknesses of this evaluation**

This is the first study to report in-depth interviews with people with persistent seizures about their experience of learning to self-manage epilepsy in groups, with participants recruited from patients attending epilepsy clinics. In this study, nested within an RCT, the number interviewed was small, but in line with guidelines on qualitative methods that focus on eliciting detailed views [29]. New evidence emerged about how the group learning method, in which facilitators encouraged sharing of feelings and comparison of attitudes and practice, met participants’ unmet needs for social peer support, and can promote behaviour change. Such evidence may explain why and how different courses vary in their effect on participants’ attitudes and behaviour. A potential weakness of the evaluation is that it taps into perceptions of PWE in the short-term of up to 6 months post-intervention. Even with this short interval six participants reported memory problems. Three had language problems that reduced their understanding in a group course. Baseline one-to-one assessments during the consenting process had not identified that group discussion requires greater language proficiency.

### Interpretation of results

Our evidence suggests that participants valued facilitated, interactive learning that allowed them to share their stories and feelings with others who were experiencing and managing epilepsy. This group process reduced their sense of isolation, and increased their self-acceptance and confidence. In other stigmatized conditions, it has been shown that social contact and first-person narratives help reduce self-stigma [30–32], and increase self-confidence. Self-confidence is posited as a key prerequisite for people to initiate and maintain changes in their self-management behaviour [5,32].

For some participants, insufficient understanding of English was a barrier to learning in a group. It may be that one-to-one advice would be better understood. For several others, their recall of what they learned was impaired, and memory problems have been well-described in epilepsy [33]. This is particularly likely in those with persistent seizures, who may require ways to reinforce their learning and practice over time.

### Implications for clinical practice and research

Clinicians work one-to-one and focus on medication management. This does not help PWE to overcome social isolation, improve their self-confidence and learn about self-management by talking with other people who have similar experience, in a supportive and safe space. This can be redressed by group interactive courses. In this study, physicians invited participants to a course that would be led by healthcare staff. There is heterogeneity in the courses described so far in the design and outcome measures used to test them [8–10,34]. This is a first attempt to understand the process of why and how group epilepsy self-management education works, or fails to do so, from the patients' perspective. From the point of view of PWE with persistent seizures, participating in expert-facilitated interactive groups provided social support and the opportunity to express negative emotions. This reduced their sense of isolation and improved their confidence to talk about their condition.

In future, group interventions could be developed and tested specifically to prevent isolation and loss of confidence, early after diagnosis, as has been done in other chronic and stigmatized conditions [30–32]. Epilepsy courses could also be evaluated in the UK for a mixture of all PWE as in Germany [8].

We know that this interactive course was appreciated by participants in terms of social and emotional support. However, participants had had epilepsy for a median of 18 years, with persistent seizures, and language or memory problems affected over 40%. In this

context, an increase in confidence and reported behaviour change may or may not translate into measurable benefit in the medium term. Interventions that are further integrated with usual primary and secondary care, and reinforced by nurses or pharmacists over time, are more expensive and complicated to evaluate. However, there is evidence that they are likely to be more effective in promoting self-management in the medium term [5,35,36]. Although integrated monitoring and advice are important in all chronic conditions, this may be particularly important for chronic epilepsy that is difficult to control.

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