

The importance of the experiences of initial diagnosis and treatment failure when switching antiepileptic drugs



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ABSTRACT

We sought to understand the issues that lead from the need to change antiepileptic drugs (AEDs) and how this may influence someone's feelings regarding swapping to another drug. We conducted semistructured interviews with 14 people with epilepsy, four months after changing from AED monotherapy. Interviews were digitally recorded, transcripts were coded independently, and thematic analysis was undertaken through group work. There were seven major themes: failure, the reason behind the failure, and the experience itself; expectations; previous experience; personality and life events; side effects; impact of diagnosis; and outcome. Clinical outcome and patients' ideas of outcome were often discordant. Each drug change arises from a position of failure that elicits strong feelings of loss of control and vulnerability in participants. Recognizing the need for counseling of targeted individuals undergoing AED change is key. Unresolved emotional issues surrounding biographical disruption following diagnosis were potent modifiers of the change process.

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1. Introduction

We live in an age of antiepileptic drug (AED) design and availability that undoubtedly have improved choice and side effects, but the proportion of people whose seizures are refractory to their first drug has not changed perceptibly since the 1960s [1,2]. The main goal of epilepsy treatment is the achievement of complete seizure freedom by tailoring the medications to the individual and to the epilepsy syndrome; the doctrine is “no seizures, no side effects”. There is no consensus as to how to proceed when the first medication fails [3]; however, polytherapy is often the only option [4]. Evidence-based guidelines such as those provided by NICE [5] document many options but are short on pragmatic guidance to unify prescribing practice. It can be assumed that first medication failure is highly disappointing for patients, and it might lead to a negative attitude to further treatment. However, there is no published evidence exploring patient experience. We aimed to study patient experience regarding drug change by interviewing

patients whose current AED was no longer appropriate for them for a variety of reasons and were undergoing a swap to another single AED.

Most research into epilepsy medication has concentrated on the balance between benefits and side effects and not necessarily on how the recipient of this medication feels about the wider aspects of medication change [6]. Qualitative research has previously identified a paternalistic approach to AED decision-making [7]. The participants failed to demonstrate that they had developed many self-management strategies or that they were on an even footing in the decision-making process. In exploring the patients' unanswered questions regarding epilepsy treatment, we identified that patients prioritize practical support for treatment problems: concerns about how to take medication are among their most important questions [8]. We undertook a qualitative analysis of people following AED change to appraise their experiences of this change and to identify common recurring themes that may help us make recommendations to improve this important and common process.

2. Methods

We identified and recruited patients through the Epilepsy Unit at the University Hospital of Wales, Cardiff, UK. All had a senior specialist diagnosis of epilepsy following appropriate investigation. The North West Wales Research Ethics Committee granted the approval (07/WNo01/

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37). Participants were eligible if they were taking a single AED and were considering changing this; the suggestion could be from the patient or from their clinician. Domiciliary interviews were conducted by a single researcher, and the audio recording was transcribed verbatim. The interviews were conducted four months after AED switch and timed for short- and medium-term concerns regarding the alteration to be gleaned. The interviews were not scheduled to have a maximum length and would be terminated by the interviewer once all questions were answered and spontaneous contributions were recorded.

The interviewer conducted a number of mock interviews on core-searchers which were appraised for quality and reproducibility. The first interviews consisted of approximately 40% scripted questions – these were written by the study group. The semistructured interview involved a mixture of open and closed questions initially covering the person's ability to cope with the diagnosis and its actual and perceived effects on all aspects of the person's life, coping with the need for AED change, and adapting to symptoms and possible drug side effects. The interview structure was critically iterative, evolving as more participants were interviewed and as potential themes began to emerge. All patients were asked about the outcome/success of their AED switch, and this was compared to the objective assessment by their clinician (as documented in their notes).

The transcripts were read by the group at intervals to identify potential themes, and these were fed back to the interviewer. The interviews were concluded when no more pertinent themes were identified, suggesting that data saturation had been achieved. The final transcripts were analyzed and coded by three researchers who independently identified the concepts that were produced by the interviews. The documents were physically annotated so that similarities and differences between the ways that the data were coded could be identified and discussed. Through group work, these codes were combined to produce themes (thematic analysis), and these themes were discussed with the whole research team. An emergent theme had to be seen in three or more interviews to be considered valid. An interpretative phenomenological approach was used [9] to develop the major themes and determine their interrelatedness. This process confirmed the utility of the seven major themes for categorizing the experiences described. These themes were interconnected because of their influence on the patient's journey and their emotional relationship with the participant. This enabled a model to be created (Fig. 2B). Illustrative quotes are provided as an illustration of the content of the themes; in places, biographical details have been changed to preserve anonymity.

3. Results

Twenty-five people were approached to take part in this project, and fourteen were interviewed (Fig. 1). Six interviewees were male. The

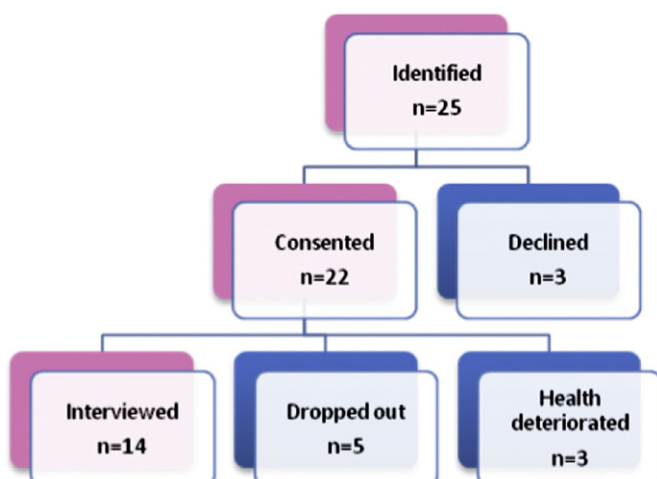


Fig. 1. Participant identification and recruitment.

mean age was 40 years (range: 17–68). Four were thought to have genetic generalized epilepsy (GGE) and the remainder, focal epilepsy. Eighty-one thousand seven hundred ninety-four words of text were analyzed (mean words per interview: 5842, range: 1075 to 10,093). Text box one describes the major themes of the interviews.

Failure	Failure was subdivided into ‘the reason’ (the circumstances surrounding the need for an AED switch) and ‘the experience’ (the emotional response to the need to change AED).
Expectations	This describes the practical and emotional aspects of the switch, particularly the decision-making process.
Previous changes	This theme included previous experience of change relating to their epilepsy (such as the results of previous AED switches, alterations to seizure types, or a change of clinician).
Life events	These include evidence of personality traits and characteristics which may influence their experience of AED switching.
Side effects	Current, past, or feared side effects were collected.
Diagnosis	This is the emotional impact of the original diagnosis with epilepsy.
Clinical outcome	This is the short-term effects of the drug change, specifically seizure control and subsequent clinic visits.

Text box one - Themes that evolved from the interviews.

3.1. Interview responses

3.1.1. Failure

3.1.1.1. The reason

“I was fit free then they said they were trying to get women of child-bearing age off Epilim yeah onto Lamictal or lamotrigine or whatever so um under the advice of the doctor at the Epilepsy Unit. I said well fine you know as long as it doesn't affect me”.

[Thirty-six-year-old female with focal epilepsy.]

“I thought [the first drug] was really good um but I said I've got a rash. ... and it's mainly on my arms and legs ... so he said ‘I'll have to take you off them’ and I think I said I tottered once or twice. He said ‘oh definitely take you off them then’”

[Sixty-eight-year-old female with focal epilepsy.]

3.1.1.2. The experience

“I still feel vulnerable even on these pills after what happened ...”
“I feel very very vulnerable I just wanna its weird.”

[Twenty-two-year-old male with juvenile myoclonic epilepsy (JME).]

“It never used to bother me really ... but now I feel a bit more nervous about going out and doing things by myself.”

[Twenty-two-year-old male with left temporal lobe epilepsy (TLE).]

3.1.1.3. Expectations

“I asked to change because I've said for years it's not working you keep on telling me to take more but I will have a fit if ... if the trigger's there.”

[Forty-six-year-old male with focal epilepsy.]

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