



The experience of discontinuing antiepileptic drug treatment: An exploratory investigation

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Summary

Objective: Between 60% and 70% of people with epilepsy become seizure free and may choose to withdraw from antiepileptic medication. Numerous studies discuss possible factors which may influence seizure recurrence following discontinuation. However, few studies attempt to explore the decision-making process from the perspective of the patient. It is believed this is the first study to explore patients' experience of discontinuing medication following a seizure-free period of 2 years.

Method: Semi-structured interviews were conducted with twelve people with epilepsy who had attempted withdrawal from their medication. All twelve of the participants lived in the North-East of England. A phenomenological approach was taken in order to gain an in depth understanding of their withdrawal decisions.

Results: Five themes emerged from the interviews. Principally, the timing of when to withdraw was a key concern, as well as the uncertainty of seizure recurrence, issues with medication and the embarrassment of being diagnosed with epilepsy. Those who unsuccessfully withdrew from medication discussed their acceptance of the condition. Mixed feelings regarding satisfaction with G.P. support were also reported.

Conclusions: Incorporating the themes into the Theory of Planned Behaviour [Ajzen I. In: Marks DF, editor. *The health psychology reader*. London: Sage; 1985] provides a model of the withdrawal decision-making process based on the experiences of those who have made the decision. There is a paucity of research investigating the withdrawal decision, therefore the findings from this study should be used for the production of appropriate and relevant information regarding the key issues which have been raised regarding withdrawal decisions and support those making the decision.

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Introduction

Although epilepsy is a chronic neurological condition, 60–70% of people with the condition may

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become seizure free for at least 2 years and be faced with the decision to withdraw from their antiepileptic drugs (AEDs).¹ Numerous reports highlight the side effects of AEDs, such as fatigue and drowsiness² and impaired cognitive function.³ With the emergence of evidence for the reversal of such effects following discontinuation, the issue of supporting people in the withdrawal decision becomes paramount.

A limited number of studies have explored the psychological impact of withdrawal from AEDs, but not the decision-making process. Baker⁴ conducted a withdrawal study and found that 2 years following AED withdrawal, there were no significant psychosocial problems evident in the study sample. Furthermore, it has been found that discontinuation of AED treatment can lead to an increase in self-esteem, and a reduction in feelings of stigma.⁵ Therefore, it appears that problems associated with having epilepsy may be reduced through a successful discontinuation of the treatment.

Within the withdrawal literature there is a predominance of research exploring prediction of seizure recurrence following AED discontinuation in an attempt to better inform and counsel people making the decision. However, no firm conclusions regarding how to predict relapse have yet been drawn from these studies. Berg and Shinar⁶ note a 10–70% relapse rate cited across the literature and more recently research has identified relapse rates of 31% for children⁷ while others cite 10%.⁸

There are numerous problems that may account for this discrepancy in relapse rates. In general the literature suffers from a wide variation in methodologies employed such as, the type of epilepsy explored, prognostic factors used, length of follow-up, randomisation procedures and age at diagnosis and withdrawal. Furthermore, a report in Frankel⁹ argued there are more psychological implications which should be taken into account in the decision-making process rather than just the physiological issues.

Interestingly, The Medical Research Council Anti-epileptic Drug Withdrawal Study Group¹⁰ found non-randomisation into a withdrawal group centred around the participant not wanting to lose his/her driving license. This highlights additional concerns in the decision-making process to seizure recurrence. Furthermore, Aktekin et al.⁷ argue people contemplating withdrawal from AEDs should get support from their physicians regarding the social consequences of discontinuing their medication.

Jacoby et al.⁵ and Perucca et al.² argue that doctors should help counsel those who are eligible for AED withdrawal, and in particular, focus on the psychosocial implications of their decision. How-

ever, there is evidence to suggest that no such support is provided. For example, The Medical Research Council¹⁰ asserts that in the UK, epilepsy sufferers who are in long term remission receive very little (if any) medical advice from their doctors. In addition, Chappell¹¹ reports that epilepsy sufferers often feel they are expected to “experiment” with their medication, and stop or reduce it themselves. Clearly this is an area that needs greater attention and research focus.

In summary, although no psychosocial problems have been found following withdrawal from AED treatment,⁴ the psychological factors considered while making the decision are not known. The majority of research in this area concentrates on predicting seizure recurrence, yet the inaccuracy of current methods and the overlooking of psychosocial considerations means the support provided by physicians in the decision-making process could be inadequate. By determining what is of importance to people with epilepsy when making the withdrawal decision, suggestions could be made as to how to provide adequate health services to support them in making the decision.

A key model of decision-making is the Theory of Planned Behaviour,¹² the strengths of which lie in its consideration of social beliefs and perceptions regarding behaviour, as well as cognitions and attitudes towards a behaviour. As psychosocial issues have been noted as concerns within the AED withdrawal process, although not adequately investigated to date, it would be interesting to explore if the findings from the current study could be incorporated into the Theory of Planned Behaviour in order to provide a clear model of the withdrawal decision-making process. Such a model could ultimately be used to direct support for people making the withdrawal decision.

The paucity of research regarding the experience of discontinuing treatment means it would be difficult to develop a reliable questionnaire to address these issues. Consequently a phenomenological approach has been adopted in the current study. Phenomenological research aims to identify the “lived experience” of a phenomena,¹³ and will concentrate on investigating the subjective “reality” of discontinuing AED medication.¹⁴

Scambler¹⁵ argues that experiential knowledge of epilepsy (i.e. the exploration of the phenomenon of epilepsy from the patient’s point of view) is important to explore in order to ensure patient needs are adequately addressed. This paper aims to explore the meaning and experience of withdrawing from AED treatment following a 2-year seizure-free period and the process of making the withdrawal decision. In turn, it may be possible to identify ways in which

health care providers can help improve services to counsel those making the withdrawal decision.

Method

Design

A qualitative approach using semi-structured interviews with open questions was used. In accordance with guidelines proposed by Husserl and In Byrne,¹⁶ bracketing was used before and during the interviews in order to ensure that any preconceptions or biases regarding epilepsy were acknowledged by the researchers and would not affect the interpretation of the results. For example, when designing the questions, care was taken so that the background research did not influence the types of questions asked, which in turn may have biased and restricted the responses of the participants.

Participants

Twelve participants were recruited, five of whom were male and seven female, with an age range of 15–56 years. The person with epilepsy was interviewed in all cases except for the 15 year old who's parents wished to take part in the interview. They had all been seizure free for at least 2 years before making the decision to discontinue AED treatment and were either making the decision to withdraw from treatment at that time, or had already withdrawn from treatment. One of the participants was making the withdrawal decision at the time of the interview; seven had successfully withdrawn from their AED medication at the first attempt (they had not experienced a seizure since discontinuing their medication); three had successfully withdrawn following a second attempt; and one participant had not been successful after three failed withdrawal attempts.

The participants were recruited via epilepsy support groups in the North East of England. Once ethical permission had been obtained, support group leaders across the region were contacted by telephone, and information letters were posted out to be given to their group members. As a result, the study sample came from a number of areas across the North East of England.

Materials

It is proposed that by obtaining a clearer understanding of the experience of living with epilepsy, this may help put into context the experience of making the withdrawal decision. As such, the interview questions began by exploring the experience of

living with epilepsy, before investigating the withdrawal decision and the experience of withdrawal. The questions began openly, regarding the effect epilepsy has had on their lives, and leading to specific areas of interest, such as medication and family influences. Further questions were also included during the interviews in order to explore certain topics introduced by the participants.

Prior to the design of the interview questions, the researcher used bracketing¹⁶ to suspend any preconceptions regarding epilepsy, which may have biased the responses of participants. Questions could have been asked such as, "How has having epilepsy affected your relationships with friends?". In comparison, questions were used such as, "Do you feel having epilepsy has affected you, and if so, in what ways?". In this way, the participants were not directed into talking about a subject which, may not have been held as important to them.

Procedure

Before the interviews could begin, consent was obtained from each participant. Permission was also sought from participants regarding their interview being audio taped. Each interview lasted between 30 min and 1 h, and took place either at people's homes, or in an office at one of the support group centres. All interviews were carried out by the same researcher, and recorded with the use of a dictaphone.

In order to improve the "credibility" of the research, "participant validation"¹⁷ was sought. Confirmatory questions were asked throughout the interviews in order to confirm the interpretations of the participants' responses made by the interviewer. For example, if a participant reported problems with their doctor, this may have inferred that this meant they were dissatisfied with the support from their doctor. In that case, they would be asked how satisfied they were with their doctor, as a means of confirming (or correcting) this interpretation.

Following the ethical guidelines outlined by the University of Teesside ethics Committee, any names mentioned throughout the interviews were changed, as well as each participant being allocated a participant number, in order to maintain anonymity.

At the end of each interview the participants were debriefed, and provided with contact numbers for NHS direct and support groups in their area (even if they were already a member of a support group).

Analysis

Once the interviews were completed, they were all transcribed verbatim, and a phenomenological

analysis was carried out, in accordance with the guidelines set out by Lemon and Taylor.¹⁸

Firstly, each transcript was read and re-read in order for the researchers to immerse themselves in the data, and get a feeling for the information which had been gathered. Secondly, significant statements which described the experience of living with epilepsy, the experience of medical support and the experience of making the decision to withdraw from treatment and the withdrawal itself, were extracted. The next stage in the analysis involved assigning meanings to each of these statements.

Following this, the statements were grouped together according to their meanings in order to develop different themes. At this point, the researchers referred back to the original transcripts in order to make sure that the meanings assigned to the statements were accurate when viewed within the whole transcript. Finally, the themes were collated, and the meanings of each theme were reflected upon in order to develop a description of the phenomena of discontinuing AED treatment and the decision-making process.

Results

Five themes emerged from the interviews (uncertainty of the future; personal issues in making the decision; it is "worth a try"; G.P. support; acceptance).

Theme 1: uncertainty of future

Initial thoughts and feelings about discontinuing medication were mixed. Participants noted the benefit of not having to take AEDs anymore, but were also concerned with the risk of seizure recurrence.

"Mixed feelings ... because yeah I was happy like the thought of coming off them, being seizure free, but its also ... frightening to think oh but you're taking a risk that you still could possibly ... like have a seizure when you come off them".

"... frightened whether, if it was going to happen again was a big thing to me because loosing control of what your doing ... what your body's actually doing, you're not aware of it ... its quite frightening so ..."

During the time when these participants still had seizures, the uncertainty and speed of onset was noted.

"Why, one minute you're alright and then the next minute you're bad ... They just came on like that (*clicks fingers*) Quick".

The main concern with seizure recurrence appears to be fear of loss of control during a seizure. Following a seizure free period of 2 years or more, it is daunting for someone to consider putting themselves at risk of losing control if a seizure was to occur following withdrawal. Ultimately, however, there is a recognition that there is just no way of knowing if seizures will recur or not and they are left to hope that the withdrawal will be successful.

"... just ... like just ... like gonna hope, for the best".

This issue of uncertainty of the future also continues following withdrawal. Although withdrawal may be successful in the short term, there is no agreed cut off point where people can be certain that they will never have another seizure. In this way the feelings of uncertainty continue from initially making the withdrawal decision, to well after discontinuation of AEDs has occurred.

"I would like to know how long before we can start breathing".

Theme 2: personal issues in making the decision

Although participants discussed a fear of seizure recurrence, this theme highlighted more personal, psychosocial issues which are also considered when making the withdrawal decision. Three sub-themes emerged from the data (embarrassment of diagnosis; medication problems; timing of withdrawal).

Sub-theme 1: embarrassment of diagnosis

The diagnosis of epilepsy was reported as embarrassing, affecting people's confidence and self-esteem. One participant even reported feeling "less of a person" because of her epilepsy.

"... in this day and age it isn't really, like the medication I take doesn't make it a problem, I'm able to drive and what have you, but its in my mind that, I don't know, I'm less of a person than what I am ..."

"... a little ashamed of it".

"I felt embarrassed about being diagnosed with it ..."

In turn, this influences the withdrawal decision in that the hope of a successful withdrawal will take away the label of epilepsy, helping the person to become "normal" again. It is felt that not taking the

AED medication will end their time as a person with epilepsy.

"I just want it out of the way, so hopefully I don't have to say, put down on forms you've got epilepsy ... Yeah, so I'm normal

Sub-theme 2: medication problems

When asked about making the withdrawal decision participants often discussed problems with their medication, both in terms of their side effects and the number of tablets they had to take each day.

"I didn't like it (MEDICATION) at first ... there was just too many of them".

"... there is a lot of side effects ... tremors, shaking ... poor concentration ... erm, mood swings ... erm ... change in appetite, change your erm sleeping patterns".

Furthermore, one participant noted that despite the fear of seizure recurrence, the side effects of his AED medication outweighed the problems which seizures caused for him.

"... what I found was the side effect of the medication was worse than the seizures".

Additionally, a further medication issue was noted by one participant who wanted to have a child. She found she would have to withdraw from her medication if she did become pregnant, as these could harm the unborn child. This highlighted a further consideration in the decision-making process specifically for women.

... I read lots of articles that basically said it wasn't a good idea (TO GET PREGNANT) and if you could possibly come off the medication then you should".

Sub-theme 3: timing of withdrawal

The timing of withdrawal was a key consideration in the decision-making process both for the adults in this study and the teenager.

"And about 4 years ago we asked, just before he started senior school because it would have been nice, so if anything was going to happen he would have still been in primary school when everybody knew him ..."

Due to medical complications this first withdrawal did not take place, but the timing was still a key consideration now as it would affect his opportunity to learn to drive.

"... now we were at the stage of getting him off them before he wants to learn to drive, 'cos if he had to go back on them, then you're losing your time".

However, the timing of discontinuing AEDs can also stop the withdrawal process. It appears that although the decision may have been made to withdraw (based on issues such as embarrassment of diagnosis, medication problems, etc.) if the timing was not right, then the withdrawal would be delayed or stopped completely.

"... like I'm going on holiday and I've put off coming off them again until I come back because I'll have to get watched in the swimming pool, and everything. It means giving up my car for six months, and that means a lot socially, how am I gonna ... get about and everything".

Theme summary

In summary, the withdrawal decision centres around a number of psycho-social and medical issues, but ultimately the timing of the withdrawal is paramount in the decision-making process. Although participants reported having made the withdrawal decision, based on their appraisal of embarrassment at diagnosis and medication issues, the withdrawal attempt could be delayed if the timing was inappropriate.

Theme 3: it is "worth a try"

Once the issues noted in the previous themes had been appraised, participants commented that it was "worth a try" to withdraw from their AED medication. After initial consideration of the impact and uncertainty of seizure recurrence, the decision was still made to "try" and discontinue their medication, providing the timing was right.

"I suppose because I felt I'd gone so long without any fits, so it was worth a try".

It is "worth" the risk of seizure recurrence in some cases because this is seen as worse than continuing their medication – the benefits of not taking AEDs outweighs the risk of seizure recurrence.

"... you think well ... OK it's worth, worth a try, I'd like to cos obviously ... you don't want to take them (AEDs) for life or whatever".

However, the participants recognised that they could only "try" to withdraw from their medication, highlighting that there was no way of knowing if they would be successful, and thereby stressing the uncertainty of the situation, stating "I take it as it comes".

Theme 4: G.P. support

When asked about the support they receive from their G.P. both for their epilepsy in general and in making the withdrawal decision, there were mixed responses. Both generally and in the decision-making process, G.P.s did not appear to be providing enough information for their patients or have referral systems in place for patients to get information and support. In turn, patients were often left to research the issue themselves without any support.

“Erm ... I think any finding out, I’ve probably done myself”.

“I felt that there wasn’t er ... enough information”.

“I asked my consultant and he said yeah no problem, as long as you’ve been, erm, seizure free for a year on your medication, no problem ... so ... and there was like no, he gave me no telephone help lines ... or anything like that”.

As well as not providing adequate information, G.P.s were perceived as having a poor knowledge of epilepsy and were not up to date with research in the area. This was particularly evident in the participant who withdrew from her medication through pregnancy. Despite approaching her G.P. before she became pregnant, the information she received was inaccurate.

“... I’d actually gone and, you know in order to seek advice as to what I should do before I got pregnant, and was just given what I subsequently realise is completely wrong advice”.

“if you get a G.P. that’s up to date on it, then fine, but if you don’t, it’s a bit of a lottery”.

On a positive note, one participant was happy with the support she had received from her G.P. This satisfaction appeared to be linked to the time and support she had received. She was given time in the consultation and her points were taken seriously. As other participants noted the lack of knowledge displayed by their G.P., this participant appeared to recognise that her G.P. may not be an expert in epilepsy, but allowed her to be the expert on her condition and on how she felt rather than imposing his/her own opinions on her and potentially providing inaccurate information.

“I can say something and it’s never ... well, “I’m the doctor round here”. But I talk to them, I put things to them, and I say” look, if my body’s not right I can feel it ...”

Theme 5: acceptance

One participant who had three unsuccessful withdrawal attempts discussed an acceptance of epilepsy now, highlighting that an unsuccessful withdrawal attempt was not necessarily detrimental to them in the long term. Although during the decision-making process the participant reported that it was worth the risk to try and discontinue AED treatment rather than continuing to take medication, with unsuccessful withdrawal this feeling was eventually reversed.

“I’d rather take it (MEDICATION) than have the problems that seizures can cause”.

“Now, I would say I don’t want to. It’s just not worth the risk”.

Although initially the risk of seizure recurrence was “worth” taking, the problems associated with recurrent seizures ultimately changed the participant’s outlook. Interestingly she noted that she was “fortunate” that her seizures were well controlled while on medication, yet this had not prevented her from attempting to withdraw from the medication initially.

“... having had three spells where I’ve come off it and had problems, erm ... you just accept it, it’s part of life, you know. But I suppose I’m fortunate and it is pretty well controlled on medication ...”

Discussion

The themes presented highlighted a number of considerations in the withdrawal decision. Initially feelings were “mixed” as people recognised the uncertainty of future seizure recurrence and considered the loss of control experienced during a seizure. This was highlighted when considering their reports of seizure occurrence prior to the seizure free period. Worry of when a seizure would occur prompted many of the participants to use techniques to ward off future seizures. Some commented that they would “keep busy”, and “self analyse” in an attempt to keep further seizures at bay. However, such strategies were performed in conjunction with taking their AED medication, yet there was still “worry” as to when the next seizure may occur. In this way, it can be seen how the prospect of not even taking medication may be very daunting. Furthermore, for those who had successfully withdrawn, the fear of seizure recurrence continued since there was no agreed point where they could be certain that they would never have another seizure.

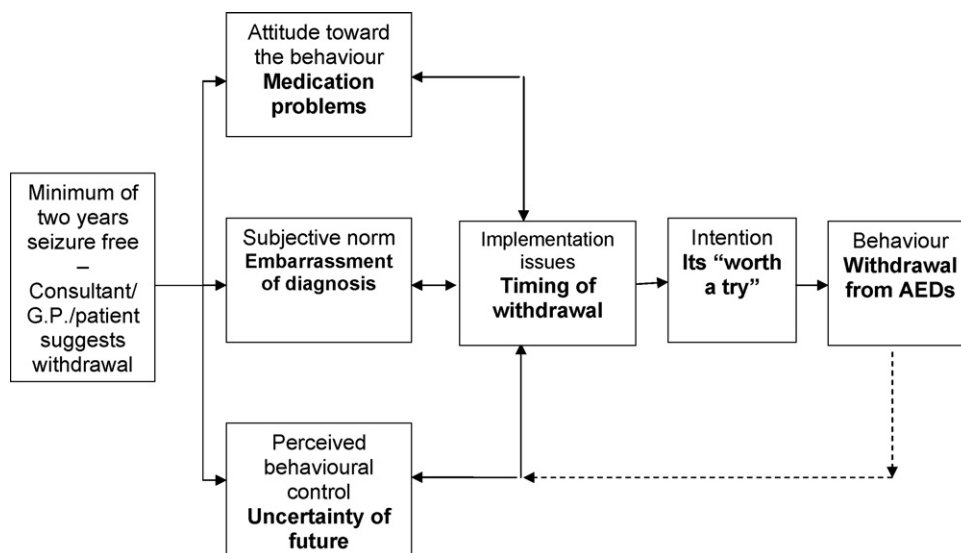


Figure 1 Model of the decision-making process: Theory of Planned Behaviour.

Despite this, the recognition that there was no way of knowing if or when a seizure would occur, led those making the withdrawal decision to consider withdrawal and “hope for the best”. However, more personal issues were still to be considered in the process. Participants discussed side effects of their medication and the wish not to take drugs for the rest of their lives, as well as the embarrassment of having a diagnosis of epilepsy. The participants reported feeling “less of a person” because of their illness and may have attempted to conceal their condition from others, in an effort to avoid the embarrassment and shame of having epilepsy. Discontinuing AED treatment meant these people would feel “normal” again. They might not view themselves as having epilepsy anymore, and therefore need not conceal their condition or feel a sense of shame at having epilepsy. This supports research by Jacoby et al.⁵ who found that following discontinuation of AED treatment, participants experienced an increase in self-esteem.

A key concern in the withdrawal decision was the timing of the withdrawal. It appears that once the personal issues and seizure recurrence had been considered, participants felt they would attempt withdrawal. However, if the timing was not optimal, the withdrawal would not go ahead. Ranganath and Ramaratnam¹⁹ argue that the physician must determine speed and timing of withdrawal, however the present results indicated people may have their own timing criteria, such as starting school or University, learning to drive and planning holidays. It is interesting that the Medical Research Council Antiepileptic Drug Withdrawal Study Group¹⁰ noted being unable to drive as a factor in the decision for adults. The current study has explored this further and

determined that teenagers and younger adults may consider timing of withdrawal as a crucial element in the decision-making process.

Given that the timing of withdrawal was appropriate for the participants, they often reported feeling withdrawal was “worth a try” and therefore attempted it. There was again recognition of the uncertainty of the future, expressing that they would “try” to withdraw from their medication. Despite the fear and uncertainty of seizure recurrence, the risk of withdrawal was worth taking. However, for those who unsuccessfully withdrew from AEDs there was an acceptance of seizures and epilepsy. Initially the risk of recurrence was worth taking, but following continued recurrence there was an acceptance of the condition.

In terms of a model of the withdrawal decision-making process, the following themes can be incorporated into the Theory of Planned Behaviour (Fig. 1).¹²

Although this model has received much criticism when applied to real life situations, in that intention does not always lead to behaviour,²⁰ as a model of decision-making for AED withdrawal, intention or the notion that it is “worth a try” always leads to the decision to discontinue AEDs. With the inclusion of “timing of withdrawal” this model could be used to identify the issues of concern to those making the withdrawal decision and the processes involved. This particular factor also satisfies a further criticism of the model, namely the disregard of implementation issues. Gollwitzer and Oettingen²¹ argue that with the addition of implementation issues, the model would consider a plan of how and when the behaviour would be carried out and thus improve the relationship between intention and behaviour.

The importance of the timing of withdrawal satisfies such a plan and thus improves the applicability of the model to the AED withdrawal decision-making process.

Despite the development of prediction criteria^{7,22} there appears to be little support for people making the withdrawal decision. The majority of participants noted dissatisfaction with the information they received from their G.P. and questioned their knowledge of epilepsy. The Medical Research Council Antiepileptic Drug Withdrawal Study Group¹⁰ found no evidence of such support being available for epilepsy sufferers who are eligible for treatment withdrawal; little seems to have changed in the intervening fifteen years. Furthermore, Perucca et al.² argue that G.P.'s should counsel their patients who are making such a decision, especially in regards of psychosocial issues, yet this support seems lacking. Although NICE Guidelines²³ advocate consultants should oversee withdrawal from AEDs, Smith and Chadwick¹ and Smithson et al.²⁴ note that those with well controlled epilepsy may be referred to their G.P. for future support and medication advice, thus examining G.P. support in this area of epilepsy care is important. However, due to the potential complexities of withdrawing from medication, ideally, patients should be supported by both their G.P. and their hospital consultant in this process. The model identified in the present study highlights the type of issues which people may need support in considering, such as the timing of withdrawal, the uncertainty of seizure recurrence and the embarrassment of being labelled with epilepsy. Although the nature of epilepsy means many of these issues cannot be answered, by listening to the concerns and experiences of those who have gone through the withdrawal decision process we may be able to support people in their consideration of such factors. G.P.s or consultants could use this model to guide their support or to refer people to appropriate information services. The identification of fear of seizure recurrence following a successful withdrawal period also highlights the need for ongoing support. However, this model should only be used as a guide for G.P.s or consultants as each patient may have their own, individual concerns about the withdrawal decision which should be addressed.

However, there were a number of limitations with the current study, such as the inclusion of people from support groups. It is often argued that people who attend support groups are those who experience more difficulties with their illness, and therefore may present a biased view of the condition under investigation. However, the nature of being eligible for withdrawal means these participants

had not experienced a seizure for at least 2 years, so they will provide a more balanced account of the experience of living with epilepsy and making the withdrawal decision. Although some participants were making the withdrawal decision at the time of the interview, retrospective accounts from the remaining participants may mean their recollections of events at the time of withdrawal are inaccurate. In the future, perhaps a sample of people making the withdrawal decision could be recruited from G.P.s or consultants. This would also allow for the opportunity to explore the decision-making process for those who do not decide to withdraw from their AED treatment. The current study is only exploratory, with a distinct focus on the experience of withdrawing from medication. Future research could explore this phenomenon further, with a larger sample, including those who decide not to withdraw from treatment.

Conclusion

By listening to the experiences of those making the withdrawal decision, this study has uncovered a number of key factors, which are inherent in the decision-making process. Namely, consideration of medication issues, the uncertainty of seizure recurrence and feelings of being diagnosed with epilepsy. A key concern appears to be the timing of withdrawal; an issue which can delay the withdrawal attempt. In turn, a model of these issues, based on the Theory of Planned Behaviour,¹² can be used to guide support for those making the decision—a service which at present is poorly provided. Although exploratory, the current study has highlighted the psychosocial implications of making the decision to discontinue medication. Further investigation in this area may inform support provision for people faced with the decision to withdraw from AED treatment.

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