



How do you exercise with epilepsy? Insights into the barriers and adaptations to successfully exercise with epilepsy



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ABSTRACT

Exercise has been shown to be a physiological and psychological benefit for people with epilepsy (PWE). However, barriers prevent many PWE from exercising safely and confidently. This research explored current perceived barriers to exercise and adaptation techniques used by PWE in order to maintain physical activity levels. Three focus groups (2–3 participants per group) and three semi-structured interviews were conducted (11 participants total). Constructive grounded theory was used to frame the study and analyse the findings, presenting new insight into the motivation, perceived barriers, and adaptation techniques used to exercise. The main motivator to maintain physical activity levels was the benefit of exercise on physical and mental health. This was shown in an increase in mood, higher social interaction, and perceived improvement in overall physical health as a result of exercise. Current barriers to exercise included a fear of injury, lack of social support, and exercise-induced seizures (e.g., through overheating and/or high exercise intensity level). Adaptation techniques used were self-monitoring through the use of technology, reducing exercise frequency and intensity level, and exercising at certain times of the day. The importance of social support was shown to provide increased confidence and positive encouragement to exercise, contrasting with family and friends worrying for his/her safety and medical professionals requesting termination of some physical activities. These findings provide new insight into current adaptation techniques that are used and developed by PWE to overcome common barriers to exercise. These new additions to the literature can lead to further development of such techniques as well as examine current medical professionals' knowledge of the benefits of exercise for PWE.

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1. Introduction

For people with epilepsy (PWE), exercise has shown to be beneficial for seizure control, decrease the side effects associated with medication, and improve overall well-being [1–3]. Furthermore, research investigating quality of life (QoL) shows the improvement in mood and QoL for PWE after a 12-week exercise program [3]. Recent qualitative research has confirmed these benefits of exercise, with participants voicing that exercise increases their physical health, decreases stress levels, increases self-esteem, positively impacts mood, and improves QoL overall [4,5]. Although both qualitative and quantitative research has presented the positive impact of sports and exercise for a person with epilepsy [1–3,5,6], the prevalence of regular exercise for a person with epilepsy is lower compared to the general public [7], as there are still common barriers (both physical and psychosocial) that prevent many PWE from feeling the benefits of exercise [4,5,8]. The main barriers to sports and exercise reported are fear of the seizure occurring [4,8], fear

of seizure-related injuries [9], stigma [5,10], and incorrect advice from medical professionals [4,5,11–13]. As a result, this inactivity has shown to cause social isolation, low self-esteem, weight gain, and depression [5,9,11].

Although the benefits of and barriers to sports and exercise have been identified, there is a lack of literature on the coping mechanisms and adaptation techniques used by PWE to exercise safely and confidently. This research was an exploratory study investigating possible barriers and coping strategies of exercising with epilepsy. Our aim was to use qualitative methods to explore ways of enhancing physical activity levels for PWE by examining the barriers to exercise, current adaptation techniques used to overcome these barriers, and common exercise activities and intensity levels.

2. Methods

2.1. Participants

Prior to recruitment, ethical approval was gained from Bournemouth University. Participants were initially recruited via Epilepsy Action's website, newsletter, and support groups around the South

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West of England. The recruitment area was extended to any region of England as a result of limited participants able to take part within the South West. Participant inclusion criteria were that each had a medical diagnosis of epilepsy; no co-morbid physical condition that could prevent exercise; at least 18 years of age or older; and live within two hours travel distance to Bournemouth. After the first two focus groups, the ability to travel was disregarded for those willing to take part in online focus groups or interviews.

Nineteen participants were initially recruited. However, as a result of participants' withdrawal prior to participating in a focus group or interview, the total number of participants who took part was 11. The total number of focus groups (2–3 individuals per group) was three. There were three semi-structured interviews. Table 1 presents the demographic data. This accounts for individuals having more than one seizure type.

Frequency and type of exercise activity varied amongst the participants. For each participant, exercise frequency depended on seizure frequency, e.g., the greater the frequency of seizures, the fewer times he/she exercised. In a week without seizures, exercise frequency ranged from 2 to 10 times per week, depending on the participant and his/her level of seizure control. For example, one participant (tonic-clonic seizures; seizure frequency varying from 1 to 2 a month to 1 every couple of months) exercised (rowing, running, strength training) at least 6–10 times a week. However, in a week that she had a tonic-clonic seizure, this would be five times or less. The average exercise frequency was 4 times per week. Walking, running, swimming, cycling, rowing, spinning, strength training, and squash were the activities undertaken. The most common activities were walking, running, and swimming.

2.2. Focus groups and semi-structured interviews

Focus groups and individual semi-structured interviews were used to explore the exercise experiences of PWE. Focus groups were chosen to 'provide a forum where participants feel more comfortable discussing sensitive issues' [14,p. 30]. Through discussing their experiences with others who have the same condition, it was intended that the participants may feel more at ease in discussing potentially sensitive topics [15]. To prevent an individual from dominating the conversation, the main researcher (SC) provided 'active people management' [14,p. 31] in order to encourage quieter participants to contribute. The first two focus groups were conducted in Bournemouth University interview rooms and the third focus group was conducted online using videoconferencing technology. Each focus group lasted 1 1/2 to 2 h. Semi-structured interviews were conducted as a result of travel limitations and low recruitment numbers. Semi-structured interviews were scheduled at a time suitable for each participant and were conducted online using videoconferencing technology. Interviews lasted 1 to 1 1/2 h each. The focus groups and interviews were audio-recorded after written and verbal consent from the participants. Pseudonyms are used to protect the participants' confidentiality.

Questions were asked around the common themes of barriers to exercise, adaptation methods, and benefits of exercise. Further, the

focus groups and interviews permitted an open discussion of themes (e.g., related to exercise adherence, social support) that may be currently absent from research. A topic guide was used in the focus groups and interviews in order to explore these themes.

Sample questions asked:

- 1) Tell me about your experience exercising with epilepsy.
- 2) What type of exercise do you do?
- 3) How often do you exercise?
- 4) What motivates you to exercise?
- 5) Are there any barriers to exercise?
- 6) How do you overcome these barriers?
- 7) Have you discussed exercise with your doctor? If so, what does he/she say?
- 8) How do your family/friends feel in regard to your exercise routine?

2.2.1. Trust and rapport

Prior to starting each focus group or interview, trust and rapport were built with the main researcher and participants through conversations on the phone, email, and in person/online. This was key in developing comfort in the research setting and to ease any of the participants' concerns prior to the start of the sessions.

2.3. Constructionist grounded theory

The focus groups and interviews were analysed using constructionist grounded theory (CGT). As CGT recognizes the impact of the researcher upon the research, this methodology was chosen as it aims to 'give a voice to the subject' [16,p.11]. Data were transcribed and analyzed using CGT in order to develop possible models that could be explored within future research. The analysis process was conducted as follows [17]: Initial coding began after the first focus group. This involved verbatim transcription followed by coding to discover the important themes that emerged. This process then led to supplementary questions for the next focus group. Following this, focused coding was conducted through refining the categories and through the use of further data collection, establishing the categories and their connections further. Next, theory development occurred. This process laid the foundations of the developing theory, leading to further interviews and refinement of the theory over time. Lastly, themes that emerged from the last focus group and interviews were then used in discussions with the earlier participants to develop the theory further. This last step involved one to one discussions with six earlier participants (via phone and/or email).

This analytical process was conducted until no new topics were discovered with this participant group and the emerging theory allowed a depiction of the barriers, benefits, and adaptation methods used by PWE to exercise. Following analysis, member checking [18] was conducted through presenting these findings back to the participants in order to assess if the participants felt that they could recognize their experiences in the findings.

2.4. Reflection

As the main researcher has epilepsy, this was discussed with the participants prior to the start of the focus groups and interviews in the case of a seizure occurring. To limit researcher bias, reflection techniques were followed throughout the research process. Such techniques included discussions with the co-author, self-reflection, and memo writing [4,5]. These reflection methods occurred prior to and after interviews and focus groups, during transcription, as well as throughout the analysis process. Reflection allowed for further development of the analysis through memo writing, allowing connections between themes, and further solidification of the grounded theory method. Great care was taken so that the researcher's experiences did not dominate the interviews or analysis. Participants remarked that due to the main

Table 1.

Gender	7 Females; 4 Males
Age	Mean: 42 years Range: 18–60 years
Seizure type	Tonic-Clonic: 11 Partial seizure: 3 Absence: 2 Myoclonic: 1
Mean time since diagnosis	18 years Range: 8–49 years
Ethnicity	White-British: 10 Black-British: 1

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