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The psychosocial impact of exercising with epilepsy: A narrative analysis

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ABSTRACT

Research has presented the benefits of and barriers to exercise for people with epilepsy through quantitative means. However, individual experiences through qualitative investigations have been absent. This research will present the narratives of people with epilepsy exercising over time and, as a result, develop further understanding of the psychosocial impact of exercising with epilepsy. Four interviews were conducted over the course of one year (one every three to four months) with four participants (aged 23–38 years) who varied in seizure type and control (16 interviews in total). A narrative analysis was used to analyze their exercise experiences. Results showed that exercise creates a positive effect on psychological and physical well-being. However, prevention from exercise as a result of medical advice or recurrent seizures can create negative effects such as social isolation, anxiety, lack of confidence, frustration, and anger. Adaptations of decreasing exercise intensity level and partaking in different physical activities are techniques used to lessen the negative impact and maintain an exercise routine. Time was shown to be an important factor in this adaptation as well as portrayed the cyclical responses of negative and positive emotions in regard to their exercise life. These findings provide valuable insight into the psychosocial benefits of and barriers to exercising with epilepsy and draw attention to the individual differences in how a person with epilepsy copes with uncontrolled seizures and their impact on his/her exercise routine. This knowledge can lead to future research in exploring how a person with epilepsy can overcome these barriers to exercise and encourage more people with epilepsy to enjoy the benefits of exercise.

1. Introduction

For most people with epilepsy, physical activity has been shown to have positive effects on seizure control and personal well-being [1]. Recently, the International League Against Epilepsy (ILAE)'s task force on sports and exercise promoted these benefits and provided clinical advice on how to exercise safely in regard to level of seizure control [2]. However, despite the physical and mental benefits of physical activity, exercise is still not a regular occurrence for people with epilepsy [3]. The main reasons reported for inactivity are the fear of the seizure occurring [4,5], fear of seizure-related injuries [6], and being inadequately informed about the possibilities of playing sports [7]. As a potential result of this inactivity, at least in part, social isolation, low self-esteem, weight gain, and depression are commonly found among people with epilepsy [7,8].

The abundance of research exploring the benefits of and barriers to exercise for people with epilepsy has been primarily quantitative and medicoscientific [4,8–10], leaving an omission in our understanding of the firsthand exercise experiences of people with epilepsy. Therefore, through the use of narrative inquiry, this research aimed to present the psychosocial impact of exercising with epilepsy over time. Providing firsthand accounts of the emotional response to the impact of epilepsy on the exercise routine of the person with epilepsy, these narratives provide the multidimensional impact of exercising with epilepsy over one year and subsequently allow further insight into the barriers to and benefits of exercising with epilepsy. In turn, this research aimed to encourage the development of methods for people with epilepsy to overcome such barriers and allow more people with epilepsy to benefit from physical activity.

1.1. Narrative inquiry

Using a social constructionist philosophy, narrative inquiry was chosen as it has been shown to promote a heightened understanding of a subject matter that is limited through the use of quantitative means [11–14]. Described as the 'linguistic form uniquely suited for displaying human existence as situated action' [13,p. 5], narratives use language as the tool to make an experience meaningful [15]. In the use of language, multiple discourses from one's experiences can be expressed, presenting the shift and changes in subjectivity, rather than a stable or fixed self [16]. As time has been shown to be significant to narrative construction [15,17], it is of importance to this research to also consider the effect of time on the exercise experiences of the person with epilepsy.

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2. Method

Participants were recruited through the Epilepsy Action UK research database and an epilepsy medical center in southern England. The three criteria for participants were the following: 1) epilepsy was the participant's main condition [18]; 2) age was 18 years or older; and 3) participant exercised at least three times a week, or would do so, were they not hindered by their epilepsy. These criteria were to ensure that exercise was important to the participant, as well as each having an epilepsy diagnosis [3]. Exercise type and seizure type were of no consequence to recruitment; however, each was noted for future research purposes. Four participants were recruited following ethical approval from the University of Roehampton. As each participant remained throughout the research process, the depth of knowledge obtained was sufficient, and therefore, no further participants were recruited. Participants' anonymity was maintained through the use of pseudonyms.

2.1. Interview process

Four interviews over the course of one year (one every three to four months) were completed with each participant (16 interviews total). Interviews were semistructured/conversational in nature to enable a ‘conversation’ with the person with epilepsy [19]. Questions of what and how, and not why, were used in order to focus on the individual's experience [20,21]. The first interview opened with the question “Describe your experiences of exercising with epilepsy” and was further developed through clarification and elaboration probes. Background questions were asked concerning exercise routine, family life, and work, as well as obtaining basic demographics. Questions for the subsequent interviews were developed through the themes identified and researcher reflection on earlier interviews. Interviews varied in time (lasting approximately an hour and a half to 4 h), took place at locations that were chosen by and comfortable for the participant (e.g., university interview rooms and quiet coffee shops), and began after written and verbal consent were obtained. Personal diaries were supplied to the participants as a supplement to the four interviews and as a tool to add depth to their lived experience [22]. Although participants read segments of the diaries aloud during interviews, these were not separately analyzed as it was agreed at the start of the research process that the collection of the diaries was voluntary.

The researcher/participant relationship was based on trust and rapport, which resulted from earlier conversations via email and/or telephone, as well as general conversation prior to the start of the interview. As the main researcher had epilepsy, where appropriate, she was willing to share aspects of her exercise experiences with the participants in order to enhance the trust and rapport built with the participants [23]. For example, the participants were able to ask questions concerning the author's own experiences of exercising with epilepsy, thus sparking them to divulge more and become more relaxed within the interview environment.

Reflection is a key methodological step within qualitative research, allowing for preconceptions to be acknowledged [24]. In order to recognize any potential limitations and/or benefits to this research due to personal entanglement, multiple reflective steps were taken (e.g., self-interview (main researcher), memo writing, reflection journal, conversations with the coauthor). These steps were taken with the aim of limiting the effect from personal experience upon conducting the interviews and the compilation of the narratives [24]. Although we acknowledge that we cannot limit all researcher effects, through reflecting throughout the course of the research, we were able to acknowledge this impact as well as view the positives of such an effects.

2.2. Narrative analysis

A narrative is defined as ‘a complex genre that routinely contains a point and characters along with a plot connecting events that unfold sequentially over time and in space to provide an explanation or consequence’ [25,p. 2]. This research used a holistic-content approach to best bear witness to the person with epilepsy's story [11,26,27] because of how it views the complete ‘story as a whole, contextualized in a culture and history, and attempts to grasp the overall pattern or guiding metaphors’ [28,p. 537]. Following interview transcription, narrative analysis began through the process of identifying themes and marking them in each margin. These themes were then organized in relation to overall importance of the individual's narrative, as well the connections to other relevant themes. The transcript was then reread to confirm that no other themes were present [27]. Next, to provide a visual representation of the thematic connections, a thematic map was developed from the present themes [11]. Discussions with the coauthor allowed for a more concrete thematic map and confirmation that the themes present reflected the interviews. The results presented below are the most common themes across each participant's narrative. Prior to presenting the findings, the background of each participant will be provided.

2.3. Participants

Gwen, 38, was diagnosed with complex partial seizures at age 11 and aimed to exercise at least three times a week. Choosing to mainly run and/or swim for exercise, Gwen discussed a constant frustration with barriers to exercise as a result of uncontrolled seizures. Currently not taking medication as she is trying to become pregnant, Gwen had intractable epilepsy with seizures occurring weekly. Married to a supportive husband, Gwen felt envious of others who were able to exercise as and when they liked, leaving her with a feeling of a lack of control of her body.

Rose, 25, was diagnosed with tonic–clonic seizures a year prior to the interviews commencing and has experienced two seizures in her life. Exercising approximately three to four times a week, her exercise type of choice was running or swimming. She expressed the benefits of exercise on her reduced feelings of stress and fatigue yet also felt frustrated at her family and friends' lack of understanding of how her epilepsy impacted her life.

Maya, 23, has had simple partial seizures since she was a young child as a result of a brain tumor. Following surgery to remove the tumor at 3 years old, she became seizure-free, but at the age of 13, the seizures returned as a result of scar tissue buildup within the brain. Depending on seizure activity, Maya competed in open-water races and swam at least four times a week, both in a swimming pool and open water. Maya was passionate about swimming and was determined to be the first person with epilepsy to swim the English Channel.

Andrew, 28, was diagnosed with tonic–clonic seizures at age 18. Exercising at least four times a week, he participated in team rowing, swimming and attended the gym. Andrew experienced seizures often during exercise. He discussed feeling very embarrassed and fearful of his epilepsy during and/or as a result of exercise and felt stigmatized by a few members of his rowing team.

3. Results

The results over the course of one year presented a varied emotional response due to uncontrolled seizure activity negatively affecting each participant's exercise routine. Varying from cycles of negative emotions as a result of nonexercise to promoting the benefits of exercise upon seizure activity and overall well-being, these narratives provide new insight into the psychosocial impact of exercise for people with epilepsy. Variables that compounded this emotional response included identity, inadequate medical advice, exercise type, social support, seizure frequency, and seizure type. The following will describe the psychosocial impact of exercising with epilepsy (effect of exercise, frustration, and anxiety) as well as the variables that helped formulate a positive and/or negative quality of life over the course of one year (seizure frequency, common physical activities, and social support).