



Self-reported exercise engagement and seizure control – A preliminary survey of people with epilepsy at a safety-net hospital

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ABSTRACT

Benefits of exercise on general health and wellbeing are undeniable. The International League Against Epilepsy has provided some guidance into exercise and sports for epilepsy. However, people with epilepsy are typically misinformed and restricted by fear and lack of evidence about exercise benefits in epilepsy. Our study seeks to investigate engagement in exercise in epilepsy at our center and identify potential barriers to physical activity. We conducted an anonymous survey at the Epilepsy Clinic using a clinically validated measure of exercise (IPAQ) at various levels: vigorous, moderate, and walking, and a questionnaire of 21 potential reasons for inactivity. Data were collected in REDCap. Statistical analysis was performed on SAS. We collected responses from 72 epilepsy participants between January and April 2024. Participants with controlled seizures were more likely to engage in moderate exercise compared to respondents with uncontrolled seizures. The top two general perceived barriers were having no one to exercise with and not liking exercise. Epilepsy-specific barriers were higher in respondents with uncontrolled seizures compared to those with controlled seizures, with the top two reasons being fear of “exercise-induced” seizures and lack of guidance on appropriate exercises. Our findings showed that there were more participants with controlled seizures who perform moderate exercise compared to those with uncontrolled seizures. Future studies are needed to evaluate whether exercise can have an impact on improving seizure control. Our study also highlights opportunities to educate health care providers, patients, and community members about exercise to facilitate engagement in exercise and improve epilepsy outcomes.

1. Introduction

Epilepsy affects over 65 million people and is considered the second most burdensome neurological disease world-wide.[1,2] Disability in people with epilepsy (PWE) is driven by two factors – seizures, and the associated co-morbidities including cardiovascular disorders, obesity, memory impairment, and poor mental health – which overall lower quality of life. Improved management of comorbidities may positively impact health outcomes. One nonpharmacological adjunct intervention proposed for PWE is physical exercise. While its benefit in controlling seizures is an area of ongoing debate, several studies have shown that exercise improves general health (e.g. cardio-respiratory efficiency and

muscle strength), and cognition in PWE.[1] Furthermore, exercise has a significant effect on the quality of life of PWE as it improves psychoactive outcomes (e.g. mood state), stress, self-esteem, and subjective somatic and psychosocial problems.[1,3–6] Nonetheless, physical inactivity is common in PWE; only 35 % meet the recommended physical activity guidelines and only 40 % with active epilepsy report walking more than 10 min in the last 7 days.[2] This may have negative health consequences such as social isolation, weight gain, low self-esteem, and depression.[4] It is presumed that the overall low rate of exercise in PWE is due to stigma, safety concerns such as fear of seizures during exercise, as well as concerns raised by family members and medical professionals.[4] Currently, data are scarce about exercise

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practices among PWE and its association with the degree of seizure control. Our study aim is to investigate exercise practices among PWE and identify barriers to exercise and the association with seizure control. We hypothesized that PWE who exercise are more likely to have controlled seizures. Identifying these barriers will help inform strategies to support physical exercise engagement in PWE and improve their health outcomes.

2. Methods

We analyzed data collected between January 1st and June 30th, 2024, from a brief prospective validated survey about exercise in epilepsy at the Epilepsy Clinic at Boston Medical Center. Survey responses were anonymous. The study was granted exemption by the Institutional Board Review. The study population included patients with clinically confirmed epilepsy diagnosis. Candidates (18 years or older) with confirmed epilepsy were identified at the clinic visit by the provider and/or by the epilepsy nurse after check-in at front desk. Patients who are unable to complete the survey (e.g. not being able to read or comprehend the English language, or had cognitive impairment) or have a physical condition limiting mobility (example: hemiparesis, cane, leg amputation, etc) were not included. The survey included questions about self-defined gender, age, age at first seizure, seizure control status (where controlled status was ≥ 12 months seizure-free), and number of current anti-seizure medications (ASMs). Physical activity and exercise status were measured using the International Physical Activity Questionnaire (IPAQ),[7–9] where vigorous and moderate activity were categorized as exercise and walking was considered a physical activity, as previously defined.[10,11] The survey also included 11 questions about general reasons for inactivity and 10 questions about epilepsy-specific reasons for inactivity (Table 1).[9].

Statistical analysis was conducted on SAS (Statistical Analysis System version 9.4, Cary, NC). Descriptive statistics were presented as mean \pm standard deviation (SD) and/or median [interquartile interval (IQI)], as appropriate. Two-sample *t*-test, Wilcoxon rank sum or Chi-square tests were used, as appropriate, for the comparison between the seizure control groups (controlled and uncontrolled seizures). Fisher's exact test was used if the assumptions underlying the Chi-square test were not met.

3. Results

3.1. Demographic Characteristics

We surveyed 72 epilepsy patients. We analyzed responses from all respondents, then compared findings between the two seizure control groups. Thirty-eight (52.8 %) were men, 32 (44.4 %) were women, and 2 preferred not to answer the gender question (2.8 %). Seizures were controlled in 45 (62.5 %), uncontrolled in 20 (27.8 %), and unknown status in 7 participants (9.7 %). Median age was 44 years (IQI [35–55]). Median age of respondents with controlled seizures was 48 years (IQI [37–56.75]), and those with uncontrolled seizures was 37 years (IQI [34–50]) and showed no significant group difference ($p = 0.167$). There were more women in the controlled (57.78 %) compared to the uncontrolled (25.0 %) seizure group ($p = 0.007$). Respondents with controlled seizures were taking up to 4 ASMs (median = 2), while those with uncontrolled seizures were taking up to 5 ASMs (median = 2) and showed no significant group difference ($p = 0.114$). In the controlled epilepsy group, a majority (73.81 %) were on 1 or 2 medications, 14.29 % were on 3, 7.14 % were on 4, and 4.76 % were not taking any ASMs. In the uncontrolled epilepsy group, a majority (73.68 %) were on 1 or 2 medications, 10.53 % were on 3, 5.26 % were on 3, or on 4 medications, and one respondent did not answer.

Table 1

Summary of responses for reasons for inactivity survey (RIS) for all respondents with epilepsy, those who have been seizure-free for at least 6 months (Controlled), and those who are not seizure-free (Uncontrolled).

Survey Items	All, N (%)	Controlled n, (%)	Uncontrolled n, (%)	p-value
General perceived barriers. A reason when I do not exercise is:				
Don't like to exercise N (all): 57, Controlled n: 38, Uncontrolled n: 19	19 (33.3 %)	15 (39.5 %)	4 (21.1 %)	0.1643
Don't have time to exercise N (all): 57, Controlled n: 38, Uncontrolled n: 19	18 (31.6 %)	13 (34.2 %)	5 (26.3 %)	0.5455
Lack of access to exercise facilities N (all): 57, Controlled n: 38, Uncontrolled n: 19	15 (26.3 %)	11 (29.0 %)	4 (21.1 %)	0.5234
Lack of transportation N (all): 57, Controlled n: 38, Uncontrolled n: 19	17 (29.8 %)	11 (29.0 %)	6 (31.6 %)	0.8378
Lack of exercise clothing N (all): 57, Controlled n: 38, Uncontrolled n: 19	8 (14.0 %)	5 (13.2 %)	3 (15.8 %)	1.000 [†]
Afraid of looking stupid or unattractive N (all): 57, Controlled n: 38, Uncontrolled n: 19	10 (17.5 %)	8 (21.1 %)	2 (10.5 %)	0.469 [†]
No one to exercise with N (all): 57, Controlled n: 38, Uncontrolled n: 19	20 (35.1 %)	14 (36.8 %)	6 (31.6 %)	0.6947
Unsure how to begin and proceed with an exercise program N (all): 57, Controlled n: 38, Uncontrolled n: 19	18 (31.6 %)	12 (31.6 %)	6 (31.6 %)	1.000 [†]
Soreness and tiredness after exercising N (all): 57, Controlled n: 38, Uncontrolled n: 19	17 (29.8 %)	11 (28.9 %)	6 (31.6 %)	0.8378
Trouble with health problems such as muscle strains or cardiovascular symptoms N (all): 57, Controlled n: 38, Uncontrolled n: 19	14 (24.6 %)	8 (21.1 %)	6 (31.6 %)	0.516 [†]
Afraid that exercise may lead to health problems N (all): 57, Controlled n: 38, Uncontrolled n: 19	5 (8.8 %)	4 (10.5 %)	1 (5.3 %)	0.656 [†]
Epilepsy-specific barriers. A major reason when I do not exercise is:				
Fear that exercise will cause seizures N (all): 58, Controlled n: 39, Uncontrolled n: 19	12 (20.7 %)	4 (10.3 %)	8 (42.1 %)	0.012 ^{*†}
Previously experienced a seizure while exercising N (all): 58, Controlled n: 39, Uncontrolled n: 19	5 (8.6 %)	2 (5.1 %)	3 (15.8 %)	0.3179 [†]
Fear of being embarrassed by a seizure while exercising N (all): 57, Controlled n: 38, Uncontrolled n: 19	15 (26.3 %)	9 (23.7 %)	6 (31.6 %)	0.5234
Advised to avoid most types of exercise by a physician N (all): 57, Controlled n: 38, Uncontrolled n: 19	2 (3.5 %)	1 (2.6 %)	1 (5.3 %)	1.000 [†]
Advised to avoid specific types of exercise by a physician N (all): 58, Controlled n: 39, Uncontrolled n: 19	6 (10.3 %)	6 (15.4 %)	0 (0.0 %)	0.1634 [†]
Concerned that exercise will interfere with antiseizure medication effectiveness N (all): 57, Controlled n: 39, Uncontrolled n: 18	2 (3.5 %)	1 (2.6 %)	1 (5.6 %)	0.5357 [†]

(continued on next page)

Table 1 (continued)

Survey Items	All, N (%)	Controlled n, (%)	Uncontrolled n, (%)	p-value
Discouraged from exercising by family and/or friends N (all): 58, Controlled n: 39, Uncontrolled n: 19	2 (3.5 %)	0 (0.0 %)	2 (10.5 %)	0.1034 [†]
Know of other persons with epilepsy who had seizures while exercising N (all): 58, Controlled n: 39, Uncontrolled n: 19	2 (3.5 %)	1 (2.6 %)	1 (5.3 %)	1.000 [†]
Do not have proper guidance on what exercises are appropriate for me N (all): 58, Controlled n: 39, Uncontrolled n: 19	18 (31.0 %)	10 (25.6 %)	8 (42.1 %)	0.2034
Fear that a seizure will occur while exercising alone N (all): 58, Controlled n: 39, Uncontrolled n: 19	14 (24.1 %)	8 (20.5 %)	6 (31.6 %)	0.5141 [†]

Note: Data are presented as count (%) for each group of responses.

* There was a statistically significant difference ($p < 0.05$) in the proportion of responses provided by individuals in the Controlled versus Uncontrolled groups.

[†] The assumptions underlying the chi-square test were not met and therefore Fisher's exact test was used.

3.2. IPAQ data

To assess the level (vigorous, moderate, and walking) and amount (days or hours) of exercise, we present responses in all respondents and then compare findings between the two groups: controlled and uncontrolled seizures. Fig. 1A summarizes the data for weekdays of exercise and amount of hours/day of sitting. Statistical comparisons were performed between those who engaged in 0 days/week versus those who engaged in 1–7 days/week of exercise (Fig. 1B).

Thirty-four respondents (49.3 %) engaged in vigorous exercise, with a nonsignificant trend towards more respondents with controlled seizures compared to those with uncontrolled seizures (Fig. 1B-i; 55.8 % and 31.6 % respectively, $p = 0.0783$).

Many respondents (64.3 %, $n = 45$) reported regular moderate exercise weekly. Individuals with controlled seizures engaged in moderate exercise more frequently than those with uncontrolled seizures (Fig. 1B-ii; 73.8 % vs 36.8 % respectively, $p = 0.009$). Most respondents (91.4 %, $n = 64$) reported walking (>10 min at least once per week). The frequency of walking was similar between the two groups (Fig. 1B-iii; 92.9 % and 89.5 %, $p = 0.642$).

On weekly average hours of exercise in a day, respondents spent 2.24 h on vigorous exercise, 1.81 h on moderate exercise, and 2.58 h on walking. Those with controlled seizures spent slightly more time on exercise compared to those with uncontrolled seizures, without a statistically significant difference at all exercise levels (Fig. 1B-iv). The American Heart Association recommends 150 min of weekly exercise. [12] In our cohort, 35 % engaged in vigorous and moderate exercise each, and 54 % engaged in walking. There was no significant difference in reported seizure control between those who engaged in more or less than 150 min of activity (vigorous $p = 0.303$, moderate $p = 0.101$, walking $p = 0.877$).

3.3. Reasons for inactivity

Most respondents completed the survey in full. Detailed responses and counts of respondents in each group (controlled and uncontrolled) are presented in Table 1. Four with unknown seizure control status were not included in analysis. The top two general perceived barriers in all respondents were having no one to exercise with (35.1 %) and not liking

exercise (33.3 %), while the top two epilepsy-specific barriers were a lack of guidance on what exercises are appropriate for them (31.0 %) and fear of being embarrassed by a seizure while exercising (26.3 %). Respondents selecting “fear that exercise will cause seizures” were significantly different between controlled (10.3 %) and uncontrolled (42.1 %) groups ($p = 0.012$). There were no statistically significant group differences for other survey items. However, the top two barriers in each group across all items differed: those with controlled seizures selected not liking exercise (39.5 %) and having no one to exercise with (36.8 %), while those with uncontrolled seizures selected lack of guidance on what exercises are appropriate for them (42.1 %) and fear that exercise will cause seizures (42.1 %).

4. Discussion

4.1. Summary of findings

In this study, we evaluated exercise habits of PWE and factors contributing to physical inactivity, focusing on the difference between those with controlled and uncontrolled seizures. Our findings suggest that individuals with controlled epilepsy are more likely to engage in more frequent and moderate-high intensity physical activity compared to those with uncontrolled epilepsy. Substantial overall barriers were cited, including having no one to exercise with, a lack of guidance surrounding appropriate exercises, and a lack of knowledge of how to begin and proceed with an exercise program. A barrier that significantly differed between groups was fear that exercise will cause seizures, with a larger number of those in the uncontrolled seizures groups indicating this as a barrier (42.1 %) compared to the controlled group (10.3 %). However, only a small portion of participants with uncontrolled seizures (15.8 %) reported previously experiencing a seizure while exercising. We acknowledge that these findings are higher than previously reported in the literature and could be due to a recruitment bias as a surgery referral center. Interestingly, respondents with uncontrolled seizures are predominantly worried about the risk for seizure and those with controlled seizures have non-epilepsy specific reasons that can be observed in the general population or other diseases.

4.2. Comparison with current literature

Our results align with existing literature. Several studies reported exercise engagement and barriers in respondents with epilepsy in general or treated with neuromodulation.[9,13–15] Our study compared exercise engagement and barriers in controlled and uncontrolled seizures participants. Debate remains about the recommended level of exercise. A meta-analysis by Duñabeitia et al. (2022) reported that moderate exercise led to a non-significant reduction in seizures.[16] Häfele et al. (2021) reported that structured exercise programs can reduce the frequency of seizures and improve overall health, further supporting our findings.[17] We found more participants with controlled epilepsy engaging in exercise, specifically moderate exercise, compared to the uncontrolled seizures group. Several studies demonstrated multiple general health benefits of regular exercise including improved quality of life, fitness levels and cognitive outcomes.[9,16,18] This aligns with our findings that those with controlled epilepsy engage in greater exercise. Similarly, the report from the International League Against Epilepsy (ILAE) Task Force on Sports and Epilepsy emphasized the positive impact of physical activity on self-esteem, socialization, and long-term health which further stresses the importance of exercise within this patient population.[3] Our study findings suggest a potential link between exercise and better seizure management as individuals with controlled seizures were more likely to engage in physical activity. This is supported by the study by Lee et al. (2022),[19] which reported a negative correlation between physical activity and seizure frequency, and the case study by van der Kop et al. (2019),[20] which documented a reduction in seizure frequency following the initiation of a high



Fig. 1. Distribution of physical activity levels in people with epilepsy. (A) Daily time spent on each exercise category: (i) vigorous, (ii) moderate, and (iii) walking. (iv) Distribution of average daily hours of sitting for each participant in each group (controlled: blue; uncontrolled: orange). (B) Respondents self-reported time spent on exercise with comparison between the two groups: controlled and uncontrolled seizures. (i) Percentage of respondents who engage in daily vigorous exercise. (ii) Percentage of respondents who engage in moderate exercise. (iii) Percentage of respondents of engage in (>10 min) walking at least one day per week. (iv) Average time (hours per day per week) spent on each exercise level. Compared to those with uncontrolled seizures, there are more respondents with controlled seizures who engage in moderate exercise ($p = 0.009$). (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

intensity fitness program.

Our study also identified several barriers among PWE, including fear of seizures during exercise and a lack of guidance on appropriate exercises. These barriers are consistent with those identified by Capovilla et al. (2016), who highlighted the role of fear, overprotection, and misinformation in discouraging physical activity among PWE.[3] Despite the significantly higher proportion with fear that exercise will cause seizures in the uncontrolled versus the controlled seizures groups, very few have experienced a seizure during exercise in both groups. Being unsure of how to begin and proceed with an exercise program and lack of transportation were similarly high in both groups, which agree

with previously reported barriers to exercise in PWE.[13–15] Mauney et al. (2024) reported a higher proportion of patients who experienced a seizure while exercising (39 %) compared to our findings.[15] This difference may be due to the greater number of people with more severe epilepsy, since they were treated with neuromodulation for drug-resistant epilepsy.[15–17] Another markedly common barrier in epilepsy respondents was having no one to exercise with which could be an indirect effect related to fear from having a seizure. Future research that includes a control group (non-epilepsy) for comparison will be helpful in determining if this is an epilepsy-specific barrier.

4.3. Suggestions for improving exercise access

Educating patients and their families about the small risk of exercise-induced seizures and the overall benefit of physical activity is a key step to overcoming these barriers. Educating providers and health care professionals to make recommendations to PWE based on the ILAE Task Force on Sports and Epilepsy report can address the barrier of not having proper guidance on appropriate exercises.[3] Structured exercise programs designed specifically for PWE should be integrated into standard care to provide clear guidelines, reduce fear, and build confidence.[4] Support groups can also play a role in encouraging regular physical activity by providing PWE with someone to exercise with.

For people with uncontrolled epilepsy, specialized interventions may be utilized including supervised exercise sessions in a medical setting. Low intensity activities like yoga can build confidence and demonstrate safety while under supervision. However, supervised moderate to high intensity exercise has differential benefits in building confidence to engage in these activities that may be perceived as being higher risk.[21,22] To address anxiety related to seizures, cognitive-behavioral therapy (CBT) could also be used. In order to incorporate a regular exercise regimen into epilepsy management, we need future studies to quantify the amount of exercise and the optimal exercise programs that would benefit PWE. Studies to implement such measures into clinical care will rely on support from clinical and research institutions.

A strength of our study was the simultaneous investigation of varying types, frequency, and duration of physical activity that PWE engage in alongside their general and epilepsy-specific barriers. Our study has several limitations. Our survey relied on self-reported data from a single center epilepsy population with a relatively small sample and no healthy controls, limiting the generalizability of our findings. Given the small sample size and anonymous survey, we did not control for all medications that may affect exercise tolerance, such as sodium channel blockers or anti-arrhythmic agents. In addition, all questionnaires were provided in the English language only and did not ask about race/ethnicity or specifics about type of epilepsy diagnosis. Our preliminary study provides the groundwork for ongoing research in our diverse patient population at one of the largest safety-net hospitals in the U.S.. Moreover, future multicenter studies would improve our understanding of the impact of exercise on epilepsy outcomes and would leverage a uniform approach to educate our patients about exercise.

5. Conclusion

Our study showed unique patterns of exercise among PWE. Compared to participants with uncontrolled seizures, those with controlled seizures were more likely to engage in vigorous and moderate exercise. This should be investigated in future longitudinal study with controlled exercise regimen. The daily amount of walking and sitting did not vary between controlled and uncontrolled seizures groups. In addition, our study highlights major barriers to exercise in PWE at our center. Addressing such barriers and developing targeted interventions could significantly improve the quality of life and overall health of PWE.

Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work the author(s) used Grammarly in order to check grammar and use concise words. After using this tool/service, the author(s) reviewed and edited the content as needed and take full responsibility for the content of the publication.

CRedit authorship contribution statement

Ariel Farb: Writing – original draft, Formal analysis, Data curation. **Joseph Sisto:** Methodology, Formal analysis, Data curation. **Janine Barrett:** Methodology, Data curation. **Abrar Al-Faraj:** Writing – review

& editing, Writing – original draft, Methodology. **Shelby Goodson:** Data curation. **Janice Weinberg:** Writing – review & editing, Methodology, Formal analysis. **Jane B. Allendorfer:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Myriam Abdenadher:** Writing – review & editing, Writing – original draft, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

2.1. Data availability

Anonymized data will be shared upon reasonable request from qualified investigators.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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