

Physical exercise habits in people with epilepsy: a survey from Brazilian population

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Abstract

This survey evaluated the Brazilian population's physical exercise habits and compared them with those from two decades ago. In this cross-sectional study, 432 people with epilepsy (PWE) assessed the questionnaire. Of these, 387 (age: 33 ± 10.58 , 81.4% women) completed the questionnaire. Among them, 60.5% were involved in regular physical activities. Among those who exercise regularly, the majority (96.5%) exercised between 2 and 5 times weekly and had been physically active for at least two years. Only 23.3% were prohibited by their doctors from participating in physical activities. Only 10% reported that seizures occur during exercise, and about half of them (55.8%) believed that exercise improves or has no effect on seizure frequency. Most (79.06%) did not or rarely believe exercise can trigger seizures. More than half (57.3%) were not afraid to have seizures during exercise or were not afraid of injury during exercise due to a seizure (69%). Most believed exercise improves cognition (80.9%), depression, and anxiety (93.8%). We revisited this scenario two decades later. In our previous study, only 15% exercised regularly, while in this survey, 58.4% routinely exercised. Our findings also align with our initial survey, indicating a low seizure frequency during regular exercise, a belief that physical activity reduces seizure frequency, and a reduction in the fear that exercise might trigger seizures. In conclusion, our results show that after two decades, there have been several improvements in physical and sports activity participation among PWE. Implementing strategies to reduce barriers to exercise for PWE and educating them on the benefits of physical activity can help improve this scenario.

Keywords: epilepsy; seizure, physical activity, sports, exercise

1. Introduction

Epilepsy is a common chronic neurological disorder with a great impact on the general health and quality of life of patients, their relatives, and caregivers [1], leading to cognitive and psychiatric problems, low self-esteem, stigma, among others. Although antiseizure medication (ASM) is the most common type of treatment for epilepsy [2], other approaches, in conjunction with conventional treatment for epilepsy, have been extensively used by people with epilepsy (PWE) [3]. Clinical and animal studies have demonstrated that physical exercise programs play an important role in this picture [4-9]. Indeed, the International League Against Epilepsy (ILAE) has reinforced the importance of physical/sports activities for PWE [10].

Despite the demonstrated benefits, PWE are considered more sedentary and do not engage in physical/sports activities at the recommended intensity or frequency compared to individuals with other chronic diseases or the general population [11-14]. PWE engage in less physical activities than their peers [15]. Although exercise and physical activity are not synonymous, in the text, we use both as an activity that is planned, structured, repetitive, and purposeful in the sense that the objective is to improve or maintain one or more components of physical fitness [16]. While the primary concern surrounding physical exercise for PWE has traditionally been exercise-induced seizures, it's crucial to acknowledge other contributing factors. These include the absence of suitable training facilities, transportation difficulties, low motivation, and apprehension about the availability of qualified instructors capable of managing such challenges [17]. Parents and caregivers also advise PWE not to participate in physical/sporting activities due to overprotection and ignorance about the benefits and risks associated with these activities. Insufficient participation may be partly due to inadequate knowledge and attitudes of health professionals about the benefits of exercise for PWE [18,19]. A recent survey revealed that while neurologists from Latin America exhibit certain knowledge gaps regarding attitudes toward physical activities for PWE, they generally hold positive attitudes towards such activities [20].

The degree of involvement in physical activities among PWE has been assessed across diverse populations in various countries [14,21-23]. Given that

80% of PWE reside in low- and middle-income countries, where typically the years of education are fewer compared to high-income countries [24], this could be a barrier to accessing this information. In 2003, our group carried out a survey to evaluate the physical activity habits of PWE in Brazil [11]. Although PWE believed that physical exercise positively impacts their treatment, the main observation of the study was that they were unsure how to begin and proceed with exercise, as well as fear of being embarrassed by a seizure while exercising. We believe that this picture has changed significantly over the years. Analyzing this scenario two decades later would involve examining whether there have been advancements in understanding the barriers and facilitators of physical activity participation among PWE. One would expect that substantial progress has been made regarding these issues.

We hypothesize that PWE are more aware of the benefits of regular physical exercise and demonstrates more active participation in physical and sports activities two decades later. Our primary objective is to assess the physical and sports activity habits among individuals with epilepsy in the Brazilian population. Additionally, the secondary objectives include evaluating their level of participation, attitudes, perceived barriers, and overall perceptions towards engaging in physical and sports activities.

2. Methods

2.1. Study design and ethical considerations

This cross-sectional study used a structured online questionnaire to identify the profile of PWE in Brazil regarding their participation in physical activity and/or sports programs. The Federal University of São Paulo Research Ethics Committee approved this study by CAEE number 71540323.0.0000.5505 and report number 6.423.215. We performed the study following the STROBE checklist.

Following the approval of the Human Research Ethics Committee, the Informed Consent Form was presented, and an initial pilot questionnaire was developed with a sample of 10 participants to assess its face validity and clarity. The time required to complete the questionnaire was recorded, and all participants provided written feedback. The average time to complete the questionnaire was approximately 10–12 minutes.

2.2. Setting and Questionnaire Development

The questionnaire aimed to collect sociodemographic data, participant profiles (9 items), epilepsy characteristics (5 items), availability of facilities for various leisure activities (7 items), attitudes towards physical exercise and participation levels (14 items), and barriers and perceptions related to engaging in physical or sports activities (33 items). The response format consisted of closed-ended questions, specifically in multiple-choice and open-ended questions. A structured questionnaire using a Likert-type scale was administered via Google Forms® and distributed through email, WhatsApp, Instagram, and Facebook. PWE were contacted through the Brazilian Association of Epilepsy, the Brazilian League of Epilepsy, and other regional Associations of Epilepsy. The announcement included a brief description of the survey's purpose and a link to participate. The survey was available from January 2023 to April 2024.

2.3. Participants

Eligibility criteria included participants who were at least 16 years old at the time of acceptance, had been diagnosed with epilepsy, had sufficient education to understand the questionnaire, completed the survey independently, and were capable of decision-making.

2.4. Variables

In this study, the primary outcome variable was physical activity participation among PWE, defined as self-reported engagement in any form of physical or sports activity. Key predictors included attitudes toward physical activities, the type and frequency of epileptic seizures, and the perceived influence of exercise on epilepsy symptoms. Potential confounders and effect modifiers included demographic variables such as age, sex, and duration of epilepsy diagnosis. Diagnostic criteria for epilepsy were based on self-report, with seizure types classified according to established guidelines.

2.5. Data Sources/Measurement

Data were collected through a structured questionnaire distributed to PWE. The variables were assessed via self-report, using questions validated in

previous studies to capture attitudes toward physical activity, types of seizures, frequency of seizures during exercise, and perceptions of exercise-induced benefits or risks. The comparability of assessment methods was maintained by ensuring that all participants responded to the same standardized set of questions, with clear instructions provided.

2.6. Bias

To minimize bias, efforts were made to address potential self-report biases by ensuring anonymity and emphasizing the importance of honest responses. Selection bias was mitigated by recruiting participants from a broad population of PWE, and we used a comprehensive recruitment strategy to reach individuals from various demographic and socioeconomic backgrounds. Recall bias was considered a limitation due to reliance on participant memory, but questions were framed straightforwardly to aid recall.

2.7. Study Size

The study size was determined based on a power calculation performed before the study to ensure sufficient statistical power to detect meaningful differences between groups. The calculation was based on previous research estimating the prevalence of physical activity among PWE, the hypothesized effect size, and the level of statistical significance set at 0.05 with 80% power.

2.8. Statistical methods

The data were analyzed using both descriptive and inferential statistics. Descriptive statistics, such as means, standard deviations, medians, interquartile ranges (for continuous variables), and frequencies and percentages (for categorical variables), were calculated to summarize the demographic characteristics and main study variables. For inferential statistics, appropriate tests were selected based on the distribution and nature of the data. In this study, categorical variables were available, and they were compared using the Chi-square test or Fisher's exact test where expected cell counts were less than five. The odds ratio (OR) was used to assess the strength of an event occurring in one group compared to another. A two-sample proportion test (Z) was conducted to compare two proportions from independent samples.

In all analyses, a p -value < 0.05 was considered statistically significant. Data analysis was conducted using the R program [25] with libraries the dplyr package [26], the rstatix package [27], effect size package [28]. For the analysis, responses of “I prefer not to say” were treated as having a negative profile ('No') due to the small number of individuals selecting this option. Samples with missing responses and those who did not consent to the terms of the study were excluded from the analysis.

3. Results

3.1. Participants

A total of 432 participants accessed the questionnaire. Of these, ten declined to participate, and twenty-two did not complete the questionnaire, resulting in 410 responses potentially eligible for analysis. After further screening, 23 participants under the age of 16 were excluded. Consequently, 387 responses were included for analysis. Details are presented in Figure 1.

3.2. Descriptive data

This survey collected 387 questionnaires completed by PWE. The respondents comprised 81.4% women aged 16 to 66 (mean age: 33.00 ± 10.58 years). Among the participants, 61.8% were white, 29.97% had higher education, 51.16% were single, 56.33% were employees, and 17.6% were undergraduate students. Further demographic information for the participants can be found in Table 1.

The map in Figure 2 illustrates the geographic distribution of survey respondents. São Paulo state has the highest representation, accounting for 30.5% of all respondents. The map indicates that respondents were included from almost all states, with only two states not represented in the survey data. This comprehensive coverage provides a broad perspective on the subject matter across diverse Brazilian regions. Detailed percentages and respondent counts for each state are shown on the map, highlighting regional variations in participation.

Based on seizure type, subjects were classified into three groups: 1- generalized, 2- focal, and 3- focal, secondarily generalized. About half of PWE presented generalized seizures (53.5%, $n=207$), followed by focal seizures

(17.8%, n=69), focal/generalized seizures (26.9%, n=104), and not determined seizures (1.81%, n=7). Two hundred and thirty-six (61%) participants had controlled seizures, and 151 (39%) had daily, monthly, and semi-annual seizures. All patients were treated with at least one type of ASM at the time of participation. Carbamazepine was the most common ASM followed by lamotrigine and sodium valproate. The five most frequent leisure activities described by PWE included enjoying cultural activities, social contact with friends, sports activities, walking, and nightlife. Interestingly, about 20% of PWE were not regularly engaged in leisure activities. Table 2 lists the leisure time activities among PWE.

3.3. Physical activity perceptions, attitudes, and barriers

Two hundred and thirty-four (60.5%) PWE were involved in regular physical activities, and 164 (42.4 %) were guided by a professional in physical education. Most (n = 226, 96.5% of the 234 responders or 58.4% of the 387 responders) exercised between 2 and 5 times weekly and had been physically active for at least two years. Concerning questions on sports habits, different sports were quoted more than once and are presented in Table 3. The five most frequent sports were walking/running (104), weight training (95), gym (24), martial Arts (21), and cycling (20). In this analysis, 23.3% (n = 90) of participants were prohibited by their doctors from participating in physical activities. Through the Z proportion test, we compared the results of the current study (n = 234 - regular physical activity = 226) with the previous survey (n = 100, regular physical activity = 15), demonstrating a significant increase in PWE involved in regular physical activities ($X^2(1) = 228.04$, $p < 0.001$).

Table 4 presents questions that included the frequency of seizures during exercise, perceived improvements in symptoms due to exercise, the impact of exercise on some epilepsy comorbidities, the influence of exercise on seizure occurrence, barriers to engaging in physical activities, and beliefs about exercise-inducing seizures. The data are presented as sample numbers, relative frequencies, and percentages, providing a comprehensive overview of the interactions between epilepsy and physical activities. Only 10% (41) of participants reported that seizures occur frequently or very frequently during or immediately after exercise, and about half of them (n=216, 55.8%) believe that physical activity improves or has no effect on seizure frequency. Thus, most

(n=306, 79.06%) do not or rarely believe that exercise can trigger seizures, more than half (222, 57.3%) are not afraid to have seizures during exercise or not afraid or rarely afraid of injury during exercise due to a seizure (n=267, 69%). For questions about ASM, 316 (81.6%) believe that ASM can never or occasionally affect physical exercise, and 71 (18.3%) think it can always or frequently affect ASM. Thus, 334 participants did not believe (n=123, 31.8%) or did not know (n=211, 54.5%) whether physical exercise can affect blood levels of anti-seizure medications. Regarding cognition and psychiatry comorbidities, most believe exercise improves cognition (313, 80.9%), depression, and anxiety (363, 93.8%).

An analysis was conducted to compare the distribution of individuals across responses between some questions. The analysis of seizure types and their opinions on the potential harm of physical exercise to epilepsy symptoms indicated no significant relationship between the type of seizure and this opinion ($X^2(3) = 3.97$, $p = 0.265$). This suggests that, regardless of the type of seizure experienced, most individuals (n = 245, 63.3%) did not believe that exercise could trigger seizures. The detailed results are presented in Table 5.

To evaluate the practice of regular physical activity and the fear of seizures during exercise or injury, we assessed the following questions: "Do you engage in regular physical activity?" versus "Fear of injury during exercise due to a seizure" and "Fear of seizures during exercise," no relationship could be established for either the first ($X^2(3) = 4.39$, $p = 0.222$) or the second situation ($X^2(3) = 5.17$, $p = 0.159$). This was due to the homogeneity among those who regularly engage in physical activity in our population sample, which makes it difficult to show a singular trend.

Similarly, we evaluated whether guided physical exercise would have a different influence under the same parameters. In this case, the questions were: "Do you engage in guided sports activities?" versus "Fear of injury during exercise due to a seizure" and "Fear of seizures during exercise." Again, no significant relationship was found for the first ($X^2(3) = 3.72$, $p = 0.293$) or the second situation ($X^2(3) = 7.52$, $p = 0.057$).

When we crossed the responses to the question "Do you engage in regular physical activity?" with "Do you believe that exercise can improve psychiatric comorbidities such as depression or anxiety in PWE?" we observed that those who exercise regularly believe that physical activity reduces psychiatry

comorbidities ($X^2(1) = 11.9$, $p = 0.0005$). Furthermore, those who engage in physical exercise are up to five times more likely to believe in reducing comorbidities than those who do not ($n = 387$, $OR = 5.07$, $p = 0.00037$, $CI [1.86 - 15.9]$).

When we crossed the responses to "Do you believe that exercise can improve psychiatric comorbidities such as depression or anxiety in PWE?" with "Are comorbidities such as anxiety, depression, and cognitive impairment barriers to exercise?" no significant differences were observed between individuals ($X^2(3) = 1.51$, $p = 0.68$). Similarly, when crossing the responses to "Do you believe that exercise can improve psychiatric comorbidities such as depression or anxiety in PWE?" with "Has regular exercise influenced the frequency or duration of seizures?" no significant differences were observed ($X^2(3) = 1.51$, $p = 0.68$). These findings may indicate that in addition to showing an improvement in psychiatry comorbidities, individuals also experienced a reduction in the frequency and duration of seizures associated with anxiety and depression episodes.

4. Discussion

This study assessed the degree of physical activity participation among Brazilian PWE. We revisited this scenario two decades later to evaluate the progress in understanding the barriers and facilitators of physical activity participation among PWE. As expected, improvements were observed in physical activity participation and regularity among PWE. Although a slight increase in physical activity involvement was observed, the regularity in exercise activities increased substantially. In our previous study, 51% of PWE participated in physical activities, but only 15% of them regularly. In this survey, of 60.5% who were involved in physical activities, 96.5% exercised between 2 and 5 times weekly and had been physically active for at least two years.

The extent of physical activity involvement among PWE has been evaluated across diverse populations in various countries [14,21-23]. Prior literature has indicated low participation in physical/sports activities [21,29], and subsequent surveys have shown similar findings. For instance, studies have demonstrated that PWE is less likely to report sufficient physical activity to meet the US Physical Activity Aerobic Guidelines than the general population [30,31].

More recently, in an interview survey conducted by US PWE from 2010 to 2017 and again in 2022, lower physical activity levels were reported, and their levels remained unchanged from 2010 to 2017 [32]. However, a recent survey indicated that 69% of PWE were interested in participating in a proposed exercise intervention study [17]. Therefore, identifying health benefits as the primary motivator for exercise in PWE can help to improve this scenario [33].

Another aspect of this study is the physical activities or sports habits chosen by PWE. The literature provides limited information about PWE's sports preferences. In general, PWE tends to choose individual sports or physical activities involving a few people. However, recommendations for PWE regarding contact or collective sports have evolved over the years, including some encouragement, according to the ILAE Task Force on Sports and Epilepsy [10]. While in the past, the preferred sports among Brazilian PWE were soccer, swimming, and gymnastics, in the present study, walking, running, and weight training emerged as the most practiced activities, aligning with the preferences observed in initial research about epilepsy and exercise [29] and in a recent US survey [34]. Stigma is one of several factors influencing the decision to be involved in physical exercise. In a study that analyzed the impact of stigma related to exercising with epilepsy, PWE reported that educating others about epilepsy can reduce stigma and consequently increase participation in team and group sports [33]. To this point, neurologists and healthcare professionals are also essential in recommending appropriate physical/sports activities. A survey of neurologists across Latin America [20] showed that most (92.5%) of neurologists advised exercise, but more than half would restrict their patients with uncontrolled seizures to exercise practice. Exercise recommendations by neurologists reported by PWE in this survey have remained mostly the same as those in our previous survey.

Concerning the impact of regular exercise on seizure frequency, only a few participants reported seizures during regular exercise. About half of them believe that physical activity improves or has no effect on seizure frequency, which was also shown in our previous survey. Thus, we did not observe a significant relationship between the type of seizure and seizure occurrence, indicating that regardless of the type of seizure they experienced, they did not believe that exercise could trigger seizures. Indeed, the literature has consistently

demonstrated that regular exercise positively impacts seizure frequency [29,35-37]. Clinical research reports either improvements in seizure control [29,35] or no increase in seizure frequency following structured physical exercise programs [38,39]. Although there are limited reports of exercise-induced seizures, it is generally accepted that physical exercise is unlikely to cause epileptic seizures. Overall, as reported by the ILAE task force on sports and epilepsy, physical and/or sports activities are unlikely to induce seizures [10].

Another analysis of our study showed no relationship when we crossed the variables, practice of regular physical activity, and fear of seizures during exercise or injury. These findings are in line with our first survey, in which only a few PWE feared that exercise could cause seizures (15%) or experienced a seizure while exercising (16%). Physical exercise participation has historically been discouraged by PWE due to fear of injury or the possibility of exercise-induced seizures [40]. Over the years, however, this scenario has evolved significantly. A study investigating the prevalence of injuries among PWE found that considerably fewer PWE experienced exercise-related injuries than the general population [41]. They also reported that sports-related injuries were three times more frequent in the general population than among PWE. A possible explanation by the authors for this finding might be the lower levels of participation in certain sports due to concerns about injuries during seizures [42].

Positive effects of exercise habits were observed in reducing psychiatric comorbidities. Cognitive impairment is common, affecting up to 50% of PWE [43-44], and few exercise intervention trials in the literature analyze the role of physical activity in alleviating cognitive dysfunction [37,45]. A study by Allendorfer's group [45] demonstrated that increased exercise levels were associated with better cognitive performance. They also found that PWE who had poor seizure control were less physically active and exhibited worse cognitive functioning compared to those who had been seizure-free for more than six months. This is supported by a randomized controlled trial conducted by Feter et al. [37], showing improvements in executive function following exercise, and an animal model of epilepsy showing exercise-induced enhancements in cognitive performance [46]. In our survey, participants consider that exercise positively impacts cognition. We noted that those who exercise regularly believe that physical activity reduces anxiety and depression. Additionally, those who exercise

regularly are up to five times more likely to believe in the benefit of improving comorbidities compared to those who do not. This subject was not included in our initial research, and no comparison can be made. Moreover, anxiety, depression, and cognitive impairment were not considered barriers to exercise by the participants, and the reduction in the frequency of seizures was associated with reduced anxiety and depression. Indeed, human studies have consistently shown that depression levels are lower among PWE who exercise regularly [47,48]. The antidepressant effects of exercise have also been demonstrated in a rodent model of depression and epilepsy [49]. A review conducted by Arida and collaborators [50] highlights the potential role of physical exercise in minimizing depression in PWE.

4.1. Strengths and limitations

While our study has provided valuable information about PWE physical/sports activities practices, attitudes, and perceived barriers, it is essential to acknowledge and address its potential limitations. Since this study relies on self-reported data, participants might be led to report behaviors they perceive as more socially acceptable, overestimating their physical/sports activity levels. Another study limitation was the PWE understanding of the words used in the questionnaire, “exercise” and “physical activity.” Although this information was included in the Informed Consent Form, these terms may have been a confounding factor. Internet accessibility between 2003 and 2023 to access the questionnaire and information about the benefits of exercise may have influenced the study outcomes. Since more than 80% of the responses were from women, our outcomes cannot be generalized to both sexes. The primary strength of this study is its nationally representative sample of adults with epilepsy. Respondents were drawn from nearly all states, with only two states not represented in the survey data. Another strength of our research is its consideration of socioeconomic status and race/ethnicity, which can influence physical exercise engagement in PWE.

5. Conclusions

In conclusion, our results show that after two decades, there have been some improvements in physical and sports activity participation among PWE. The

most significant progress in this scenario is the increase in exercise regularity compared to our first survey. Other aspects, such as barriers and facilitators to physical activity in PWE, have also evolved over the years. This progress has been obtained since the first scenario about the physical exercise habits of Brazilian PWE. After that, we launched campaigns to stimulate PWE to become more active [51]. To this point, actions to educate health professionals and sports instructors about the benefits of these activities for PWE have been developed. Within education, a key priority is emphasizing the positive effects of physical activity among epileptologists. Accordingly, in several editions of the Latin-American Summers Schools on Epilepsy (LASSE), students and tutors have included and discussed this issue. This knowledge can be used to develop strategies to minimize and/or overcome the obstacles preventing PWE from engaging in physical/sports activities.

Acknowledgment

This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) - Finance Code 001, and by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES-PRINT #88881.310490/2018-01), by the Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq #302689/2022-2; 308703/2023-5) and by the Fundação de Amparo à Pesquisa do Estado de São Paulo (FAPESP #2022/10696-1).

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