Epilepsy & Behavior Reports 24 (2023) 100632

Contents lists available at ScienceDirect

Epilepsy & Behavior Reports

journal homepage: www.elsevier.com/locate/ebcr

Do people with epilepsy want to participate in an exercise intervention randomized controlled trial? – Results of a brief survey and its preliminary application

Brandon S. Mitchell [a,1], Christian Puzzo [b,1], Charity J. Morgan [d], Jerzy P. Szaflarski [b,c,e], Johanna L. Popp [b], Ricardo Ortiz-Braidot [b], Anna Moyana [b], Jane B. Allendorfer [b,c,e,*]

[a] University of Alabama at Birmingham, Department of Psychology, Birmingham, AL, USA
[b] University of Alabama at Birmingham, Department of Neurology, Birmingham, AL, USA
[c] University of Alabama at Birmingham, Department of Neurobiology, Birmingham, AL, USA
[d] University of Alabama at Birmingham, Department of Biostatistics, Birmingham, AL, USA
[e] University of Alabama at Birmingham, UAB Epilepsy Center, Birmingham, AL, USA

ARTICLE INFO

Keywords:
Exercise
Epilepsy
Survey
Recruitment
Research participation

ABSTRACT

Our goal was to survey people with epilepsy (PWE) about their interest in and factors that may influence willingness and ability to participate in an exercise randomized controlled trial (RCT). A brief survey was administered to 100 PWE asking if they would take part in a hypothetical 6-week exercise intervention RCT. Follow-up questions queried reasons for and against participation and why participation would be difficult. Sixty-nine percent of respondents indicated willingness to participate. The top reason for participation was "to improve overall health with exercise" (n = 49). The top reason for why participation would be difficult was they "do not have a reliable source of transportation" (n = 27). The top reason for not participating was "not interested in research participation" (n = 19). Preliminary results were used to budget for transportation in a prospective RCT (NCT04959019). Of the first 27 PWE enrolled (63 % female; 44 % African American/Black), six (50 % female; 50 % African American/Black) have used the transportation service. The majority of PWE surveyed were interested in participating in an exercise RCT, but some indicated barriers. Accommodating transportation in an ongoing RCT has facilitated recruitment of PWE who would otherwise not be able to participate. Barriers to participation should be accounted for when designing studies.

1. Introduction

Epilepsy is a debilitating brain disease affecting approximately 50 million people worldwide [1] and over 3.4 million people in the United States alone [2]. Epilepsy is a worldwide public health problem, with prevailing treatment gaps and it accounts for over 0.5 % of the global burden of disease [1,3]. Persons with Epilepsy (PWE) not only suffer from seizures and increased risk of premature mortality, but also from comorbid conditions, including depression, anxiety, and cognitive deficits, in addition to encountering social stigma and hardships like the inability to drive and limitations on daily autonomy [1,4–6]. Increased physical activity and exercise have known health benefits including the potential to mitigate comorbid conditions in epilepsy, but studies have shown that people with epilepsy are not as physically active or do not engage in as much physical activity or exercise as those without epilepsy [7,8].

Limited exercise intervention trials suggest that exercise may ameliorate cognitive dysfunction [9–12] and improve physical and emotional mood states [13], psychosocial function [14], mood disturbance [15,16], and overall quality of life [14,15] in PWE. The high potential for multifaceted benefits in the application of exercise in PWE warrants further investigation. However, exercise intervention studies typically involve routine visits to the site of exercise training, usually several times a week, and can range from 6 weeks to 6 months in duration [9,11,13–15,17,18]. For these reasons, participation from PWE in exercise research may be difficult, particularly for those with poorly

* Corresponding author at: University of Alabama at Birmingham, Birmingham, AL, USA.
E-mail address: jallendorfer@uabmc.edu (J.B. Allendorfer).
[1] Authors contributed equally.

https://doi.org/10.1016/j.ebr.2023.100632
Received 19 July 2023; Received in revised form 9 October 2023; Accepted 2 November 2023
Available online 4 November 2023

controlled seizures who are dependent on others for care, support, and transportation. The caregiver burden is particularly high for patients with poorly controlled epilepsy, and likely also factors into the ability of PWE to participate in research [19–21].

In general, participant recruitment for human clinical trials can be challenging, particularly for randomized controlled trials (RCTs). However, RCTs are necessary for providing the highest level of evidence for recommending clinical strategies, diagnostic testing, interventions, and treatments in the patient care setting [22,23]. Most RCTs fail to meet their recruitment goals [24–26]. One meta-analysis of 114 United Kingdom multicenter trials from 1994 to 2002 found that only 31 % of studies met their original recruitment goals, and 53 % of trials extended the recruitment period [27]. It may be very difficult for populations with limited autonomy to participate in research because of a variety of reasons including limited transportation, aversion towards additional appointments and procedures, and other time commitments [28]. Lack of motivation to participate in research, independent of the potential obstacles, also negatively affects recruitment. The most important motivations for research participation by the general population are the desire to help others and the potential for the personal benefit received from the trial intervention(s) [29,30]. However, motivation for research participation may vary in clinical populations.

A handful of studies have investigated reasons for PWE to be physically active or inactive, and whether or not they would engage in exercise activities. A qualitative study in PWE identified that physical and mental health benefits of exercise as the main motivator for exercising while barriers included fear of injury or seizures, and not having social support [31]. One U.S. survey showed that in 37 PWE whose seizures interfered with their ability to exercise, “Fear of seizures” (63 %) and “Safety concerns” (66 %) were also top-rated exercise barriers, whereas in the 146 PWE in which seizures did not interfere with exercising, “lack of motivation” (46 %) and “other factors” (23 %) were the top factors [32]. Another U.S. survey showed that in 40 active vs. 93 inactive adults with epilepsy, top barriers were lack of time (48 % vs. 47 %), lack of exercise facility access (35 % vs. 46 %), not having transportation (28 % vs. 30 %), and not having anyone to exercise with (21 % vs. 37 %); inactive PWE also indicated health problems as a barrier (tied as their top third reason at 37 %) [7]. The top four epilepsy-specific barriers for active vs. inactive PWE were “fear of being embarrassed by a seizure while exercising” (18 vs. 38 %), “fear that exercise will cause seizures” (8 % vs. 23 %), “advised to avoid specific types of exercise by a physician” (both 18 %), and “discouraged from exercising by family and/or friends” (13 vs. 19 %) [7]. A similar survey of adults with epilepsy in South Korea showed the top three general barriers to exercising for 74 active vs. 104 inactive PWE are “tiredness after activity” (64 % vs. 73 %), “do not have time for activity” (55 % vs. 68 %), and “unsure how to begin and proceed with activity programs” (23 % vs. 39 %), while the top three epilepsy-specific barriers were fear of seizure during the activity (64 % vs. 65 %), family and/or friends discouraging them from the activity (46 % vs. 56 %), and having previously experienced a seizure during activities (19 % vs. 34 %) [33]. While the previous surveys gauged reasons for or barriers to exercising and engaging in physical activity in general for PWE, it is unclear if there are similar reasons when choosing to participate in an exercise intervention research study.

Recent systematic reviews illustrate that sample sizes for in-person exercise intervention studies with PWE that require multiple exercise training visits are small, ranging from 8 to 40 [8,17]. A consensus is that larger RCTs are necessary to provide higher quality level of evidence for effects of exercise in PWE, but information on level of interest by PWE and reasons for wanting to participate or not would be helpful for facilitating such trials. Thus, the aims of the brief survey administered in the current study were to first determine what proportion of our local epilepsy patient population would be interested in participating in an exercise intervention study, and secondly, to better understand some of the factors that may influence their interest and/or willingness to participate or not. We hypothesized that decisions for study participation would be influenced by several factors, specifically personal motivation, time constraints, access to transportation, and personal views regarding research participation.

2. Materials and methods

2.1. Participant recruitment

This study was approved by the University of Alabama at Birmingham (UAB) Institutional Review Board and provided a waiver of informed consent for survey participants (IRB-161108004). Medical records were reviewed to identify eligible participants. We recruited 100 adult participants with epilepsy from the outpatient clinic at the UAB Level IV Epilepsy Center and the Epilepsy Monitoring Unit (EMU). The study included participants who were at least 18 years old at the time of enrollment, had been diagnosed with epilepsy, were fluent in English, and were capable of decision making. Demographic information for the participants can be found in Table 1.

2.2. Procedure

Surveys were administered either in person or over the phone. Surveys administered in person were given to patients to complete during appointments at the outpatient clinic or EMU. Patients were given a short survey that asked about their interest and ability to participate in a hypothetical 6-week exercise training study to help determine whether exercise can improve cognitive function in people with epilepsy. A brief description of the hypothetical exercise intervention study were provided for the participants to reference while answering the survey questions. Participants of the hypothetical study would exercise 3 times a week for 6 weeks, for a total of 18 sessions. Participants would undergo an MRI and cognitive testing at the beginning and end of the 6 weeks of training. The data collected from these initial and final visits would be compared to provide investigators with insight regarding if and how exercise may improve cognitive functioning in people with epilepsy and what mechanisms may be involved.

The first part of the survey document contained the rights of the patient while participating in the survey, an explanation of the survey’s purpose, a description of the hypothetical exercise intervention study, and a brief demographics section asking the age and sex of the participant. The second part of the survey document consisted of four questions. The first survey question asked if the patient would agree to participate in the hypothetical study proposed in the survey, and the only answer choices were ‘Yes’ or ‘No’. This first question was intended to gauge interest in participating in a hypothetical exercise RCT regardless of logistical issues or other reasons that might prevent actual participation. The last three questions and the possible answers are stated exactly in Figs. 1-3 and considered independent of the first question. Respondents were allowed to select multiple options under each question and provide a reason not stated or additional reason if they did not think the available options sufficed. The three questions probed for reasons related to why a participant would participate in the hypothesized study (Fig. 1), reasons that would make participation difficult (Fig. 2), and reasons that would make participation not possible

Table 1
Study sample characteristics.

		F	M	Total
N		62	38	100
Mode of Contact	***Phone***	36	19	55
	Outpatient	7	7	14
	EMU	19	12	31
Age	***Mean***	40	39	39
	SD	15	15	15
Yes, willing to participate	***Count***	41	28	69
	Percentage	66 %	74 %	69 %

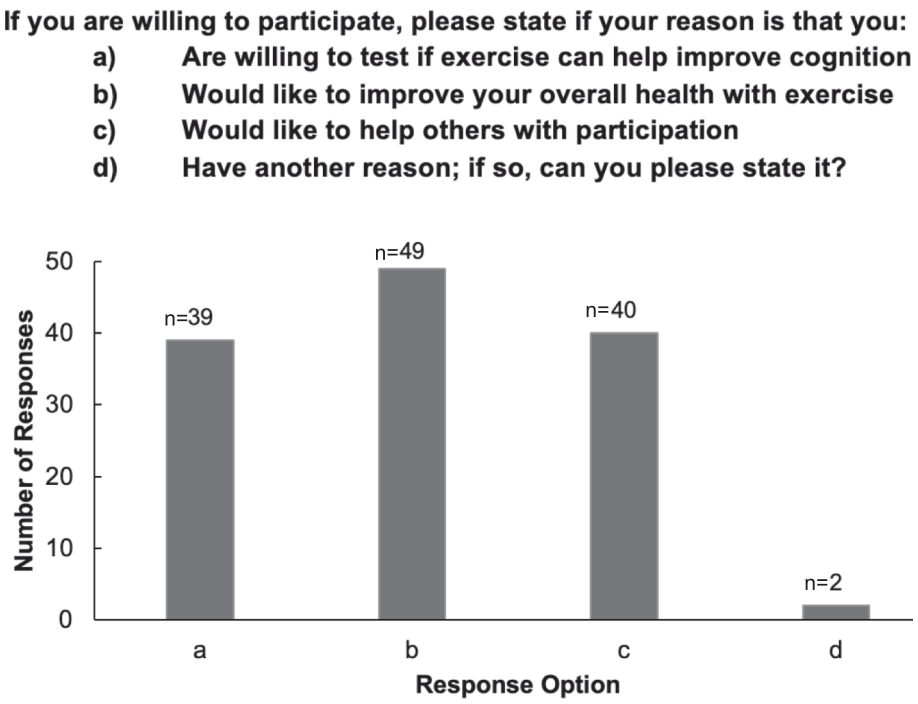

Fig. 1. Survey item questioning reasons for exercise trial participation and corresponding responses.

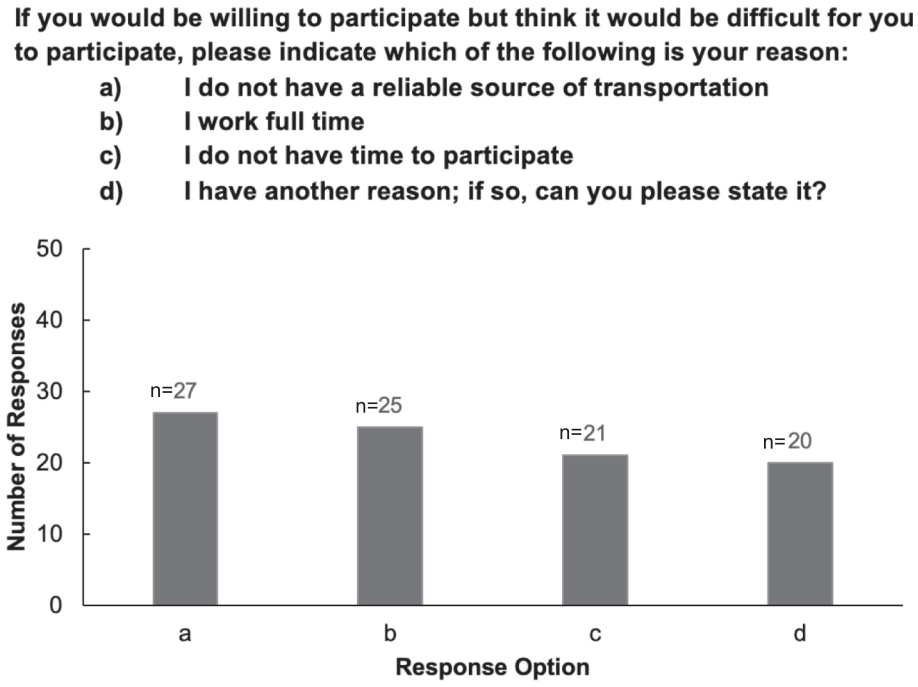

Fig. 2. Survey item questioning reasons that would make exercise trial participation difficult and corresponding responses.

(Fig. 3). After the three probing questions, the patients were asked if they wanted to provide any additional comments regarding the hypothesized study.

2.3. Analysis

IBM SPSS Version 28 was used for all statistical analyses. A binary logistic regression was used to model the dichotomous dependent variable derived from the first question of the survey instrument: "If a study like this was offered to you, would you be interested in enrolling? Yes / No (circle one)." The independent variables included two demographic variables, which included patient age and biological sex. An independent samples *t*-test was used to see if there was a difference in the ages between female and male respondents. A chi-square test was used to determine if there were differences between males and females in their responses of 'Yes' or 'No' to the first question of agreeing to participate in the hypothetical study.

For the first question, the percentage is reported for the total proportion of participants willing to participate in the hypothetical study. For the latter three questions indicated in Figs. 1-3, participants were

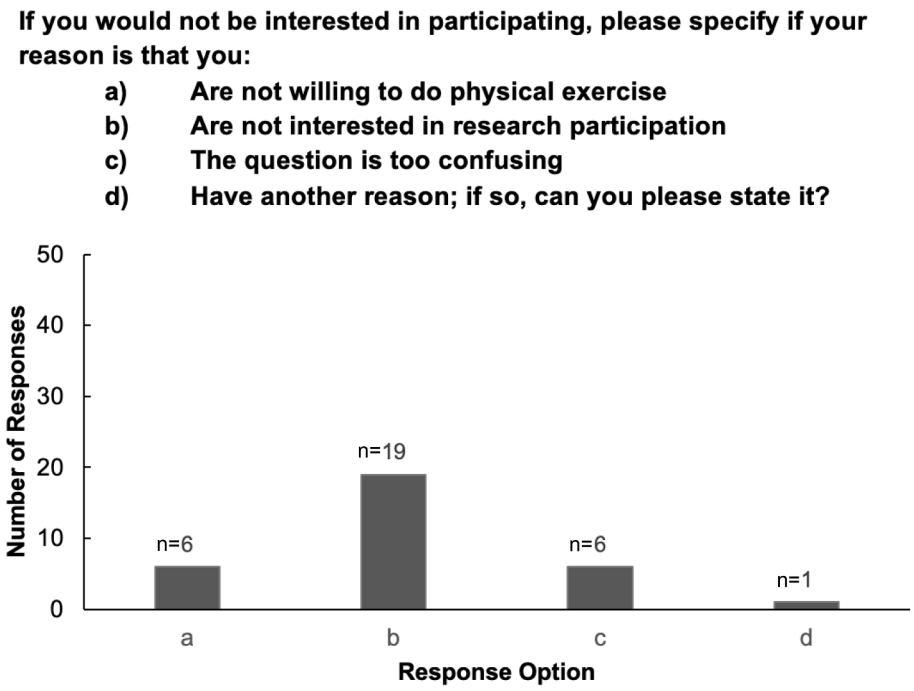

Fig. 3. Survey item questioning reasons for not participating in an exercise trial and corresponding responses.

allowed to select multiple options under each question, as stated above. Since responses could vary depending on the option(s) chosen by the participant, counts were used and the total number of respondents for each question are provided in Table 2**.** For participants who chose the 'other' option, responses were re-coded if they gave a reason that was already listed in one of the questions. For example, in the question illustrated in Fig. 2, one participant who chose the 'other' option for Question 3 and commented they "work too much," was recoded as choice 'b' for Question 3 which states that they 'work full time' since their reasoning in their comment fit into an already defined category.

3. Results

Overall, 69 % of respondents (66 % of the 62 females and 74 % of the 38 males) indicated they would participate in the hypothesized research study (Table 1). An independent samples *t*-test confirmed there was not a significant difference in the ages between the male and female respondents, $t(97) = -0.188$, $p = 0.852$. A chi-square test indicated that females and males were not different in their choice to participate in the hypothesized study, $\chi^2(1) = 0.629$, $p = 0.428$. A binary logistic regression indicated that age ($\beta = -0.005$, $p = 0.719$) and biological sex ($\beta = 0.463$, $p = 0.322$) were not significant predictors of the choice to participate with the model only accounting for 1.6 % of the variance in whether a patient chose 'Yes' or 'No', $\chi^2(2) = 1.148$, $p = 0.563$, Nagelkerke $R^2 = 0.16$.

Responses on Questions 2 through 4 were not filtered by a participant's answer to Question 1. Therefore, the number of responses could vary for each question and participants could choose multiple answer choices per question. The average number of responses given on Questions 2 through 4 was 2.56 for 100 participants. A total of 23 participants chose the 'other' option with 3 participants giving a reason that was already listed in one of the questions. The total number of responses for each question and prompt are listed in Table 2.

Table 2
Counts for each reason and total responses for the three probing questions.

	a	b	c	d	Total
Reason if *Yes*	39	49	40	2	**130**
Reason if *Difficult*	27	25	21	20	**93**
Reason if *No*	6	19	6	1	**32**

The standout feature of this tabulation was Question 3 (*Reason if Difficult*), response 'd' (Fig. 2), which had 20 responses that did not fit within the prompts given. For 17 of the 20 'other' responses, most were in response to the research site being too far or inconvenient ($n = 10$), having a lack of confidence or ability to complete the exercises ($n = 5$), and having to rely on a parent for participation for teenaged adults aged 18 and 19 ($n = 2$). The three 'other' responses did not include a comment for the reason.

4. Discussion

This survey provides insight into the willingness and practical obstacles that potential participants with epilepsy may face when they are recruited for participation in exercise research studies. Most respondents (69 %) expressed interest in participating in the proposed hypothetical exercise intervention study. The top reason for being willing to participate is to improve their overall health (Fig. 1), consistent with the focus group results from Collard and Ellis-Hill (2017) identifying health benefits as the main motivator for exercise in PWE [31]. It should be noted that without knowing the expected rate of participation for an exercise study, it is difficult to assess whether 69 % of PWE willing to participate in an exercise intervention RCT is a robust result. While many studies do not provide the level of detail to ascertain attempted recruitment of those who meet criteria versus actual enrollment of qualified PWE into exercise studies, there are a handful of reports that allow us to glean such information. For instance, our survey result is consistent with a large study of PWE in which 88.7 % (110 of 124) of those eligible for the home-based exercise intervention consented to participate in the RCT [18] and with the E-MOVE RCT that aimed to improve exercise behaviors in PWE in which 30 of the 47 (64 %) who met all inclusion criteria consented to participate [16]. However, the 69 % of PWE in our survey interested in participating is higher than the 40 % (16 of 40) who were eligible and enrolled in a pilot in-person 6-week exercise study by our group [9]. This discrepancy may potentially be accounted for by those in our survey who responded that they would be willing to participate but think it would be difficult for various reasons

(Fig. 2). These results, along with the proportion of people who indicated that they would not be willing to participate in an exercise RCT warrant further discussion.

Many survey respondents noted real-world problems that would limit or negate their ability to participate. For instance, transportation, travel distance, and lack of time, all make participation in research difficult. Other obstacles that might prevent participation include the lack of physical ability or confidence to participate in a physical exercise program, as indicated by some of the open-ended responses provided in our survey. For PWE specifically, it has been previously noted that PWE are anxious about seizures affecting their ability to exercise safely [7,31–34], and less than 50 % of PWE previously surveyed reported high confidence in the exercise they were prescribed [35]. However, there is guidance stating that it is safe for PWE to exercise without restrictions if they have been seizure free for at least 12 months, and even if one is not seizure free there are some sports activities that are permitted without restrictions while participation in others can be permitted with a neurologist's discretion [36]. Despite the evidence suggesting it is safe, PWE are still hesitant to participate in physical exercise even if they are seizure free [37]. The current survey did not ask about seizure interference, but interestingly, none of the 11 comments/open-ended responses provided for Questions 3 and 4 (i.e., if difficult to participate, or if they would not participate) had themes related to fear of seizures or to seizures affecting their ability to participate in the exercise RCT. Instead, the themes centered around issues with distance, inconvenience, lack of confidence or ability to complete exercises, and reliance on a parent for participation. Overall, our survey suggests that researchers should consider these reasons, along with the top-rated factors of transportation and lack of time, when designing their exercise intervention studies in PWE.

Similar surveys have been conducted in exercise-based studies in non-epilepsy populations such as breast cancer [38,39], spinal cord injury [40], and the general population [41] that have identified common barriers to exercise participation. An example for overcoming the transportation barrier would be accounting for rideshare or taxi costs to bring in participants with limited transportation. Additionally, researchers might consider being more flexible in scheduling study visits (e.g., outside of the standard eight-hour workday or on weekends) to include participants with daily time commitments like work or school. Home-based approaches for exercise interventions and remote monitoring of physical activity may also be considered to address barriers related to time and distance [18,42], although these may have their own unique sets of challenges such as the low adherence levels (26.7 %) indicated by Vooturi et al. (2023) [34]. Interestingly, one could interpret that "lack of time" barrier may be related to lack of motivation, as illustrated by a study in which only 6.5 % of PWE who adhered to the exercise program compared to 77.6 % of non-adherent PWE agreed with the statement "I don't get around to doing my exercises" [34]. A possibility for increasing motivation to exercise for PWE is to better educate them on the benefits of exercise, particularly since that is a top reason provided previously by PWE for exercising [31] and in the current study for being willing to participate in an exercise RCT. Another strategy may be to improve knowledge of the benefits of exercise in PWE amongst their caregivers [43], neurologists [44] and health-care professionals in general [31,45,46] that may provide PWE with additional support and motivational boost to engage in exercise.

There were also 31 % of participants who were not willing to participate, with the top reason being not interested in research participation (Fig. 3). Other potential difficulties in enrolling research participants include patient hesitancy due to past research malpractice and over-sampling of specific demographic pools. Specific to the state of Alabama, past research ethics violations like the Tuskegee Syphilis Study have led to some hesitancy for those identifying as Black/African American to participate in clinical research [47] despite accounting for 68.7 % of the Birmingham population [48]. The hesitancy towards research participation due to historical ethics violations [47], mistrust, and/or lack of comfort with the clinical trial process [49] have been noted as barriers to increasing diversity in RCT participants. These issues were not specifically queried in our study, and while they were not included in the open-ended comments by respondents, it may be helpful to address these in future surveys assessing reasons for participating versus not participating in research. It is important to consider that with any study, there is the limitation of sampling bias of people who are willing to participate in clinical research, especially when the target population is a clinical population with limited numbers. Researchers must try to instill confidence in the people they wish to include as study participants to ensure a more inclusive and representative sample of the population they are targeting.

While this survey instrument provides useful data to help guide future research design to accommodate more potential participants, it is limited by the minimal demographic and clinical information that were collected. For instance, more detailed demographics (e.g., race/ethnicity and income levels) and the type of epilepsy, would have provided important information. Given that social determinants of health, including socioeconomic status and race/ethnicity, have been proposed to affect physical activity and exercise engagement in PWE [43], this additional information would be helpful for identifying potential areas for research into how participant diversity may be increased when recruiting for RCTs. Another limitation of the survey is that the hypothetical exercise intervention did not provide the specific details of the exercise itself such as, for example, the type of exercise, duration of sets and repetitions, the duration of each exercise session. It is possible these details might have influenced the response of the survey participants and they should be included in future surveys.

Despite the shortcomings of the current survey, it was useful for the planning stages of an RCT to allow researchers to appropriately budget for providing transportation for a percentage of participants and allow for more flexible scheduling, regardless of race/ethnicity or socioeconomic status. The study sample was also reliant on patient contact and did not survey PWE living in the community who were not patients at UAB. The decision to administer the survey over the phone, in the outpatient setting, and in the Epilepsy Monitoring Unit was intended to closely resemble to environments where we recruit for research studies, though it is important to note that in-patient recruitment might require additional considerations for participant comfort. However, the number of participants is modest (N = 100), and the results of this survey could inform other researchers who conduct RCTs, particularly longitudinal studies with multiple visits, about the reasons people give that either facilitate or impede participation. Reasons such as work, school, transportation, or caregiver reliance are applicable to many populations that researchers wish to recruit from and are relevant to both pharmacological and non-pharmacological treatment studies. Unique barriers for study recruitment to exercise intervention research are comments regarding lack of confidence or ability to complete the exercises, which were previously reported as factors also affecting adherence to exercise [34].

The limitations of the survey instrument used in this study make it difficult to make demographic inferences. However, it should be noted that the information gained from this survey, particularly with regards to transportation influencing study participation, was utilized to help plan for an RCT of exercise in people with idiopathic generalized epilepsy (IGE) that is currently ongoing (NCT04959019). The first 27 participants in our current RCT (Fig. 4) are comprised of 17 (63 %) females, a proportion reflecting the slight female predominance in IGE [50]. Notably, 6 of 27 participants (about 22 %; 3/6 female; 3/6 Black/African American; 1/6 seizure-free) have utilized the rideshare transportation provided by the current RCT, allowing us to recruit those who otherwise would not have been able to travel to the facilities. This proportion is similar to the 27 % of the survey respondents who indicated that transportation would make it difficult to participate in the hypothetical exercise RCT despite interest. Additionally, our current RCT has enrolled a higher percentage (about 44 %) of Black/African

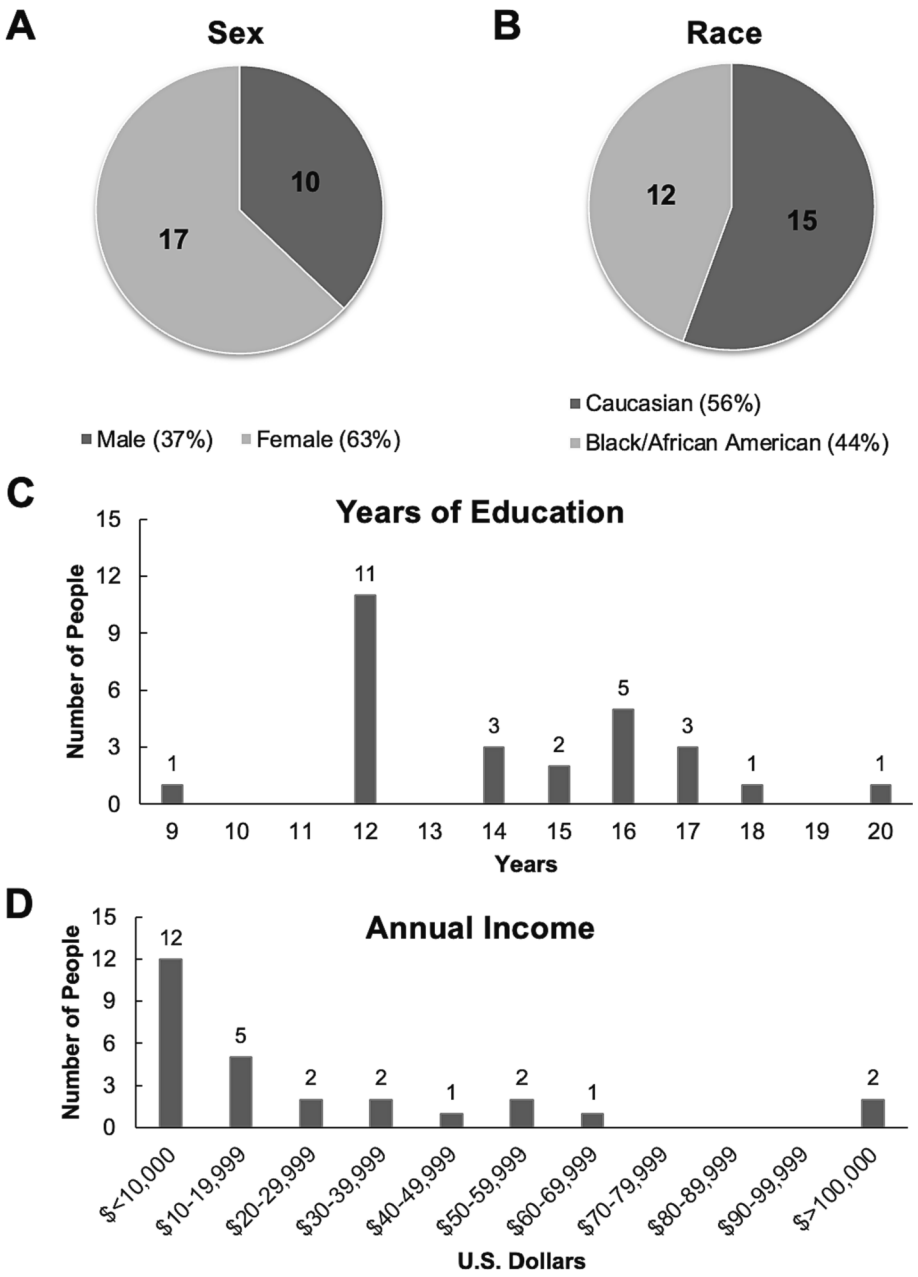

Fig. 4. Demographic information for the first 27 participants in an ongoing randomized controlled trial of exercise intervention in people with epilepsy (NCT04959019).

American participants compared to the approximately 20 % that make up the patient pool at the UAB Epilepsy Center. Considering that about 68.7 % of the Birmingham population identify as Black/African American [48], the racial makeup of our current RCT suggests that we may have increased potential to recruit a more diverse study sample. The recruitment progress of our current RCT also illustrates the real-world utility of the brief survey in study planning to help overcome barriers for RCT participation, which ultimately benefits the community through a more representative sample.

As previously noted above, the information gleaned from our study can be difficult to attain from published clinical trials, which often report only the number eligible who declined to participate (e.g., as indicated in CONSORT diagrams) without documenting the specific reasons for declining. This was the case for both the Dustin et al. (2019) study in which only 64 % (30 of 47) of PWE who met all inclusion criteria consented to participate in the E-MOVE intervention [16] and the Allendorfer et al. (2019) study in which only 40 % (16 of 40) of PWE who were fully screened and met inclusion criteria were enrolled in the exercise intervention [9]. A recent RCT of exercise intervention in Parkinson's disease had a similar 40 % rate in which only 71 of the 177 who met study inclusion criteria were randomized, since 43 "Declined to participate" and 63 were excluded for "Other reasons" [51]. This underscores the utility of the current survey and similar studies that specifically probe factors that may influence a person's willingness to participate in RCTs. Future implementations of survey instruments to provide insight into the obstacles that bar potential research participants from participating would be highly useful. Collecting demographic data like race, occupation, and annual income would allow for data analysis that could specify the parts of the target population that face the most obstacles when considering research participation. Interestingly, about 78 % of our current RCT participants report an annual income level at about or below the median household income in Birmingham, AL of

about $39,403 (Fig. 4) [48], which suggests that a lower income level may not be a significant barrier to trial participation. Additionally, replicating this survey study in other etiologies would be useful for research targeting different clinical populations. The approach utilized by Lai et al. could be a good way to design a survey by not only gaining the insight from participants one-on-one, but also by surveying the participants in focus groups to gain the social perspective of a group of participants that share a common condition [40]. Future surveys should contain this dynamic approach to gaining the perspective of the participants, as well as the shared perspectives of participants with shared conditions, and can be analyzed along with demographic variables such as age, sex, education level, relationship status, and socioeconomic information.

5. Conclusions

People with epilepsy indicate various obstacles preventing them from participating in an exercise RCT, such as transportation and time issues, despite an overall desire from most to participate in research. Previous surveys highlighted the hesitancy PWE experience when considering exercise engagement due to safety concerns and embarrassment that stem from having seizures while exercising [7,32,33]. This survey provides insight into additional obstacles that may hinder participation. Researchers can use this knowledge to develop strategies to minimize and/or overcome the effect of the obstacles preventing PWE from participating in exercise intervention RCTs.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: JPS is the Editor-in-Chief of *Epilepsy & Behavior Reports*, associate editor of *Journal of Epileptology*, editorial board member for *Epilepsy & Behavior*, *Journal of Medical Science*, and *Folia Medica Copernicana*, and receives royalties from Elsevier; receives funding from NIH, NSF, DoD, Shor Foundation for Epilepsy Research, UCB Biosciences, NeuroPace Inc., SAGE Therapeutics Inc., Serina Therapeutics Inc., LivaNova Inc., Greenwich Biosciences Inc., Biogen Inc., Eisai Inc., State of AL; is on consulting /advisory boards for PureTech Health, Biopharmaceutical Research Company, LivaNova Inc., UCB Pharma, AdCel Pharma, iFovea Inc.; has served on the Alabama State Medical Cannabis Study Commission (nominated by Gov. Ivey); serves on the Alabama Medical Cannabis Commission (2021–2025; nominated by Dr. Scott Harris, State Health Officer). JBA is associate editor of *Epilepsy & Behavior Reports*; receives funding from NIH, McKnight Brain Institute, DoD, LivaNova Inc.; has served as a consultant for LivaNova, Inc.; has received honoraria from Cleveland Clinic and University of Auckland and travel funds from the International League Against Epilepsy; serves on a Data Safety Monitoring Board (University of Alabama at Birmingham/University of Colorado Anschutz Medical Campus); serves on the American Epilepsy Society Scientific Program Committee. The rest of the authors have no disclosures to declare.

Acknowledgements

The study was presented in part at the 2020 American Epilepsy Society Meeting and at the 2023 International Epilepsy Congress and was supported in part by the Eunice Kennedy Shriver National Institute Of Child Health & Human Development of the National Institutes of Health under Award Number R01HD102723 (to JBA). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References

[1] W. HO. Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.
[2] Zack MM, Kobau R. National and state estimates of the numbers of adults and children with active epilepsy – United States, 2015. MMWR Morb Mortal Wkly Rep 2017;66:821–5.
[3] Kwon CS, Wagner RG, Carpio A, Jette N, Newton CR, Thurman DJ. The worldwide epilepsy treatment gap: A systematic review and recommendations for revised definitions - A report from the ILAE Epidemiology Commission. Epilepsia 2022;63:551–64.
[4] Gilliam F, Kuzniecky R, Faught E, Black L, Carpenter G, Schrodt R. Patient-validated content of epilepsy-specific quality-of-life measurement. Epilepsia 1997;38:233–6.
[5] Collings JA. Psychosocial well-being and epilepsy: an empirical study. Epilepsia 1990;31:418–26.
[6] McCagh J, Fisk JE, Baker GA. Epilepsy, psychosocial and cognitive functioning. Epilepsy Res 2009;86:1–14.
[7] Roth DL, Goode KT, Williams VL, Faught E. Physical exercise, stressful life experience, and depression in adults with epilepsy. Epilepsia 1994;35:1248–55.
[8] Johnson EC, Helen Cross J, Reilly C. Physical activity in people with epilepsy: A systematic review. Epilepsia 2020;61:1062–81.
[9] Allendorfer JB, Brokamp GA, Nenert R, Szaflarski JP, Morgan CJ, Tuggle SC, et al. A pilot study of combined endurance and resistance exercise rehabilitation for verbal memory and functional connectivity improvement in epilepsy. Epilepsy Behav 2019;96:44–56.
[10] Feter N, Alt R, Häfele CA, da Silva MC, Rombaldi AJ. Effect of combined physical training on cognitive function in people with epilepsy: results from a randomized controlled trial. Epilepsia 2020;61:1649–58.
[11] Eom S, Lee MK, Park JH, Jeon JY, Kang HC, Lee JS, et al. The impact of an exercise therapy on psychosocial health of children with benign epilepsy: a pilot study. Epilepsy Behav 2014;37:151–6.
[12] Eom S, Lee MK, Park JH, Lee D, Kang HC, Lee JS, et al. The impact of a 35-week long-term exercise therapy on psychosocial health of children with benign epilepsy. J Child Neurol 2016;31:985–90.
[13] Nakken KO, Bjorholt PG, Johannessen SI, Loyning T, Lind E. Effect of physical training on aerobic capacity, seizure occurrence, and serum level of antiepileptic drugs in adults with epilepsy. Epilepsia 1990;31:88–94.
[14] Eriksen HR, Ellertsen B, Gronningsaeter H, Nakken KO, Loyning Y, Ursin H. Physical exercise in women with intractable epilepsy. Epilepsia 1994;35:1256–64.
[15] McAuley JW, Long L, Heise J, Kirby T, Buckworth J, Pitt C, et al. A prospective evaluation of the effects of a 12-week outpatient exercise program on clinical and behavioral outcomes in patients with epilepsy. Epilepsy Behav 2001;2:592–600.
[16] Dustin IH, Resnick B, Galik E, Klinedinst NJ, Michael K, Wiggs E, et al. The feasibility and impact of the EMOVE intervention on self-efficacy and outcome expectations for exercise in epilepsy. J Neurosci Nurs 2019;51:95–100.
[17] Alexander HB, Allendorfer JB. The relationship between physical activity and cognitive function in people with epilepsy: a systematic review. Epilepsy Behav 2023;142:109170.
[18] SudhindraVooturi LA, Jayalakshmi S. Evaluation of factors influencing obesity and the effect of a 12-week home-based exercise program in people with epilepsy - Randomized control trial. Epilepsy Behav 2020;110:107148.
[19] Hansen B, Szaflarski M, Bebin EM, Szaflarski JP. Affiliate stigma and caregiver burden in intractable epilepsy. Epilepsy Behav 2018;85:1–6.
[20] Lee MM, Lee TM, Ng PK, Hung AT, Au AM, Wong VC. Psychosocial well-being of carers of people with epilepsy in Hong Kong. Epilepsy Behav 2002;3:147–57.
[21] Thompson PJ, Upton D. The impact of chronic epilepsy on the family. Seizure 1992;1:43–8.
[22] Bamman MM, Cutter GR, Brienza DM, Chae J, Corcos DM, DeLuca S, et al. Medical rehabilitation: guidelines to advance the field with high-impact clinical trials. Arch Phys Med Rehabil 2018;99:2637–48.
[23] Halperin JL, Levine GN, Al-Khatib SM, Birtcher KK, Bozkurt B, Brindis RG, et al. Further Evolution of the ACC/AHA Clinical Practice Guideline Recommendation Classification System: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. J Am Coll Cardiol 2016;67:1572–4.
[24] Charlson ME, Horwitz RI. Applying results of randomised trials to clinical practice: impact of losses before randomisation. Br Med J (Clin Res Ed) 1984;289:1281–4.
[25] Hussain-Gambles M. South Asian patients' views and experiences of clinical trial participation. Fam Pract 2004;21:636–42.
[26] Jenkins VA, Fallowfield LJ, Souhami A, Sawtell M. How do doctors explain randomised clinical trials to their patients? Eur J Cancer 1999;35:1187–93.
[27] McDonald AM, Knight RC, Campbell MK, Entwistle VA, Grant AM, Cook JA, et al. What influences recruitment to randomised controlled trials? A review of trials funded by two UK funding agencies. Trials 2006;7:9.
[28] Ross S, Grant A, Counsell C, Gillespie W, Russell I, Prescott R. Barriers to participation in randomised controlled trials: a systematic review. J Clin Epidemiol 1999;52:1143–56.
[29] McCann SK, Campbell MK, Entwistle VA. Reasons for participating in randomised controlled trials: conditional altruism and considerations for self. Trials 2010;11:31.
[30] Rosenbaum JR, Wells CK, Viscoli CM, Brass LM, Kernan WN, Horwitz RI. Altruism as a reason for participation in clinical trials was independently associated with adherence. J Clin Epidemiol 2005;58:1109–14.

[31] Collard SS, Ellis-Hill C. How do you exercise with epilepsy? Insights into the barriers and adaptations to successfully exercise with epilepsy. Epilepsy Behav 2017;70:66–71.
[32] Ablah E, Haug A, Konda K, Tinius AM, Ram S, Sadler T, et al. Exercise and epilepsy: a survey of Midwest epilepsy patients. Epilepsy Behav 2009;14:162–6.
[33] Han K, Choi-Kwon S, Lee SK. Leisure time physical activity in patients with epilepsy in Seoul. South Korea Epilepsy Behav 2011;20:321–5.
[34] Vooturi S, Lakshmi ANR, Jayalakshmi S. Adherence to exercise in people with epilepsy. Eur J Physiotherapy 2023;25:162–7.
[35] Kobau R, DiIorio CA, Price PH, Thurman DJ, Martin LM, Ridings DL, et al. Prevalence of epilepsy and health status of adults with epilepsy in Georgia and Tennessee: Behavioral Risk Factor Surveillance System, 2002. Epilepsy Behav 2004;5:358–66.
[36] Capovilla G, Kaufman KR, Perucca E, Moshe SL, Arida RM. Epilepsy, seizures, physical exercise, and sports: A report from the ILAE Task Force on Sports and Epilepsy. Epilepsia 2016;57:6–12.
[37] Popp JL, Szaflarski JP, Kaur M, Martin RC, Brokamp GA, Terry DM, et al. Relationships between cognitive function, seizure control, and self-reported leisure-time exercise in epilepsy. Epilepsy Behav 2021;118:107900.
[38] Sander AP, Wilson J, Izzo N, Mountford SA, Hayes KW. Factors that affect decisions about physical activity and exercise in survivors of breast cancer: a qualitative study. Phys Ther 2012;92:525–36.
[39] Gollhofer SM, Wiskemann J, Schmidt ME, Klassen O, Ulrich CM, Oelmann J, et al. Factors influencing participation in a randomized controlled resistance exercise intervention study in breast cancer patients during radiotherapy. BMC Cancer 2015;15:186.
[40] Lai BW, Rimmer JH, Yates A, Jeter A, Young HJ, Thirumalai M, et al. Critical factors influencing the decision to enroll in a physical activity intervention among a predominant group of adults with spinal cord injury: a grounded theory study. Spinal Cord 2021;59:17–25.
[41] Abraham JM, Feldman R, Nyman JA, Barleen N. What factors influence participation in an exercise-focused, employer-based wellness program? Inquiry 2011;48:221–41.
[42] Akerlund S, Varkey E, Klecki J, Zelano J, Ben-Menachem E. Randomized controlled trial of moderate cardiovascular exercise for patients with drug-resistant epilepsy. Epilepsy Behav 2021;124:108335.
[43] Hansen B, Allendorfer JB. Considering social determinants of health in the relationship between physical activity and exercise engagement and cognitive impairment among persons with epilepsy. Front Rehabil Sci 2022;3:923856.
[44] Arida RM, Sales E, Teixeira-Machado L, Prado GFD, Gutierre RC, Carrizosa J. Neurologists' knowledge of and attitudes toward physical exercise for people with epilepsy in Latin America. Epilepsy Behav 2022;131:108705.
[45] Vancini RL, Andrade MS, de Lira CAB. Can lack of knowledge of health professionals on epilepsy and exercise prescription be a barrier to exercise practice? Epilepsy Behav 2017;75:269.
[46] Shawahna R, Abdelhaq I. Important knowledge items with regard to the benefits of exercise for patients with epilepsy: Findings of a qualitative study from Palestine. Epilepsy Behav 2020;108:107099.
[47] Gamble VN. Under the shadow of Tuskegee: African Americans and health care. Am J Public Health 1997;87:1773–8.
[48] U.S. Census Bureau. QuickFacts Birmingham city, Alabama. In: United States Census Bureau; 2022. https://www.census.gov/quickfacts/birminghamcityalabama.
[49] Clark LT, Watkins L, Pina IL, Elmer M, Akinboboye O, Gorham M, et al. Increasing diversity in clinical trials: overcoming critical barriers. Curr Probl Cardiol 2019;44:148–72.
[50] Christensen J, Kjeldsen MJ, Andersen H, Friis ML, Sidenius P. Gender differences in epilepsy. Epilepsia 2005;46:956–60.
[51] Amara AW, Wood KH, Joop A, Memon RA, Pilkington J, Tuggle SC, et al. Randomized, controlled trial of exercise on objective and subjective sleep in Parkinson's disease. Mov Disord 2020;35:947–58.