Being physically active with epilepsy: Insights from young people and their parents

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ABSTRACT

Introduction: Researchers have called for innovative tailored interventions to address specific challenges to physical activity (PA) engagement for young people with epilepsy (YPE). Working with YPE and their parents, this study aimed to identify barriers and facilitators to adoption and maintenance of PA among YPE prior to and during the COVID-19 pandemic.

Methods: Ten YPE (all female) and their 13 caregivers, and five additional caregivers to males (N = 18; 72% mothers), completed virtual focus group sessions prior to and during the COVID-19 pandemic. Trained Child Life specialists asked questions about barriers and facilitators of PA engagement experienced by YWE, which included a specific focus on the impact of epilepsy.

Results: Thematic analysis of the data identified both epilepsy-specific and generic themes that impact PA participation among YPE. These included: (i) epilepsy experience/impact and accommodation; (ii) safety precautions; (iii) concern about seizures; (iv) social connections and acceptance; (v) parent and family support; (vi) intrapersonal self-regulation and motivation; (vii) health benefits; and (viii) key factors in common with all youth.

Conclusion: This study provides valuable insight into diverse social-ecological health factors that impact PA participation among YPE from two key stakeholder perspectives (YPE and their caregivers). By understanding these lived experiences, providers can better tailor individual support for YPE and their families to foster and maintain a healthy active lifestyle.

1. Introduction

Engaging in adequate amounts of physical activity, limiting sedentary pursuits such as recreational screen time, and accruing adequate sleep duration—collectively referred to as “movement behaviors”—have been found to have individual and additive beneficial effects for the physical, mental, and social health of young people (Tremblay et al., 2016; Fanning et al., 2017). Recent findings from two empirical studies have demonstrated that young people with active epilepsy (YPE) are significantly less likely to meet the 24-hr movement guidelines concurrently compared to their peers without chronic health conditions (Ronen and Janssen, 2019; Brown and Ronen, 2021). Evidence from Brown and Ronen (2021) suggests that limited adherence to 24-hr movement guidelines among YPE is largely attributable to below-average rates of physical activity and may be due to very low rates of sport participation. This observation aligns with findings from a population-based study showing that people with epilepsy were more likely to use walking as a leisure physical activity and less likely to be involved in ice hockey, weight training, and home exercise (Gordon et al., 2010). Moreover, a study that found that membership of a sports club was the only identified facilitator of PA among YPE also supports this contention (Ng et al., 2017).

Abbreviations: ILAE, International League Against Epilepsy; PA, physical activity; RCT, randomized controlled trial; YPE, Young people with epilepsy.

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Myths and unfounded assumptions about the dangers of YPE engaging in PA may seriously limit participation and ultimately be detrimental to these young people’s health and life quality (Thomson et al., 2014). Exercise, a purposeful form of leisure-time physical activity, has been shown to reduced epileptiform activity on EEG (Arida et al., 2008). Cross-sectional studies involving adults with epilepsy have shown that PA is associated with diverse mental health benefits (de Lima et al., 2013; Hafele et al., 2017). Such work has led researchers to advocate for PA promotion in YPE as part of an integrated 24-hr movement approach, trusting this might improve various facets of their biomedical and psychosocial wellbeing (Ronen and Janssen, 2019). Given the disparities in PA participation, the International League Against Epilepsy (ILAE) has recognized the need for innovative individualized strategies to address PA barriers specific to YPE (Capovilla et al., 2016). Despite this attention, a critical issue exists: there is an overall lack of sufficient evidence to inform individually devised interventions to be considered when promoting PA for adults or YPE or designing interventions to get this population more active (Johnson et al., 2020).

Focus group explorations in adults with epilepsy have identified social support, familiarity with the benefits of PA, worry, and lack of medical advice to participate in PA as factors related to being physically active (Collard et al., 2017). Focus groups have also been conducted among children with disabilities and their parents regarding PA participation (Shields and Synnot, 2016). Yet the current knowledge regarding facilitators and challenges to PA among YPE stems partly from our earlier work, a strength of which was the use of different methodologies (Brown et al., 2019; Willis et al., 2018). Our research group completed a multi-center randomized controlled trial (RCT) that explored the effects of an enhanced walking program on the health, functioning and quality of life of children with active epilepsy, with a mean age of 11.37 (SD 1.91) yr., who received a PA monitoring device (Fitbit) as well as a personal counselling intervention. The six-month intervention incorporated fundamental behavior change techniques, including goal-setting for numbers of steps, feedback, social support and self-regulatory skill development, and was delivered over the phone by one researcher or a trained research assistant. The quantitative analysis demonstrated that the intervention did not increase PA compared to controls over time during the six-month intervention period (p > .05). However, the study sample was heavily skewed towards relatively active participants (~9000 steps/day), who may already possess self-management skills that enabled them to achieve high PA levels and therefore have less room to gain from a behavioral counseling intervention targeting self-regulation of PA (Brown et al., 2019).

Shortly following the intervention, YPE who received personal coaching to increase their PA engagement, and their parents, completed semi-structured interviews and shared perspectives about their experience, identifying that PA had positive effects in many aspects of their lives such as: general wellbeing, increased energy level, maintaining focus, increased family time, having fun, improved independence, good mood, improved time-management and allocating time for PA, ability to self-motivate, adjustments from a sedentary lifestyle to an active lifestyle, and adapting goal setting (Willis et al., 2018). The findings were thematically analyzed according to the International Classification of Functioning, Disability and Health (WHO 2001) to provide healthcare professionals a universal approach on how to select points of entry for potential interventions. Although our quantitative study phase did not meet its first objective of increasing PA (Brown et al., 2019), the findings raised important research questions that are addressed in this current study. These include (i) identifying barriers and facilitators of PA in YPE, and (ii) understanding how providers can better support PA in YPE by using direct feedback from the population of interest. The purpose of the present study was to identify, using focus groups, the challenges to and facilitators of PA engagement directly from the perspective of YPE as well as their caregivers. Through a socio-ecological model of health lens, a comprehensive approach was undertaken that considered intrapersonal, interpersonal, environmental, and societal factors (Klansowski, 2017). These findings could provide authenticity and content validity for future development of patient-reported outcome measures (PROMs) on the topic.

2. Methods

2.1. Participants and recruitment

Convenience sampling was used to recruit participants for this study. Using phone and email, we recruited only YPE and their caregivers who had participated in the previous PA-based RCT (Brown et al., 2019) and had consented to being contacted about future studies. Both participants who completed the previous study and those who withdrew were contacted. All participants were outpatients at McMaster Children’s Hospital (Hamilton, Ontario, Canada) or Children’s Hospital of Eastern Ontario (Ottawa, Ontario, Canada).

2.2. Data collection

Participants were invited to join one-hour focus group sessions facilitated by two Child Life specialists using confirmed methodologies (Ronen et al., 2001). The specialists took field notes and used a prepared facilitator question guide (see supplement) before opening the discussions to impromptu deliberations. Interview guides included questions about PA related to the impact of epilepsy on their participation as well as intrapersonal, interpersonal (e.g., peers and family), environmental, and societal factors that influence PA adoption and/or maintenance. A key aspect of these sessions included having participants identity previous facilitators and barriers to PA engagement experienced while enrolled in our randomized controlled trial (Brown et al., 2019), and exploring how these factors have evolved since.

Each focus group session was conducted virtually using the Zoom online teleconferencing platform. Virtual focus groups allowed the researchers to gain insight about the research questions, while at the same time being easy and convenient for participants. Focus groups for caregivers were separated by mothers and fathers. Youth focus groups were planned to be divided by gender, and then into two age groups, 11–15 years, and 16–19 years. These age ranges were chosen to facilitate greater ease in dialogue and sharing of thoughts among participants with similar age- and gender-related experiences. A minimum of five participants was planned for each focus group session. However, in two of the groups one participant was unable to attend. We conducted six focus group sessions from 2018 to 2020: two with female youth (one for females 15–16 years old (n = 5) and one for females 17–20 years old (n = 5)); three with mothers (n=13); and one with fathers (n = 5). We were unable to recruit enough male YPE for a focus group (n = 3). To facilitate transcription, sessions were digitally recorded with both audio and video formats and transcribed verbatim. Focus groups were conducted until the point of saturation of information. It should be noted that the study began prior to the COVID-19 pandemic and continued during it, which allowed for the inclusion of additional questions pertaining to the impact of COVID-19 on PA participation among YPE. Four focus groups were conducted before the pandemic and two were conducted during it. Participants were provided a $25 CAD gift card as a token of appreciation for their time.

2.3. Data analysis

The transcripts were analyzed using thematic analysis, which is a systematic approach to identify, analyze, and report patterns (themes) within data. The protocol by Braun and Clarke (2006) was used and consisted of five steps: (i) familiarization with the data by reading through the transcripts in an active way, without making notes or trying to identify the themes; (ii) generating codes (to facilitate this step, we organized and grouped pieces of the data into possible themes and
patterns); (iii) searching for themes by sorting the codes into potential themes and collating all the relevant coded data extracts within the identified themes; (iv) reviewing themes, both at the level of the coded data extracts and in relation to the entire data set; and (v) naming and defining the themes and subthemes by identifying the essence of each theme and its importance in the broader context.

We approached the thematic analysis in an inductive or “bottom-up” way, where the themes identified are strongly linked to the data themselves (Braun and Clarke, 2006). AW led the thematic analysis. AW, CH, and SP each independently read the transcripts, created codes, and identified themes. AW, CH, and SP cross-checked each other’s notes and came to a consensus about the themes through discussion. These steps were repeated with input from the other authors until no new information was detected. This process helped ensure consistency and rigor throughout the thematic analysis phase. The results from the analysis were organized according to themes that reflect the essence and spirit of the discussions.

2.4. Ethics

All study activities were approved by and conducted in accordance with the McMaster University’s and Children’s Hospital of Eastern Ontario’s ethics review boards. Informed consent was obtained from all participants.

3. Results: thematic analysis

We identified eight themes, with four specific to having epilepsy and four that are generic to the experiences of young people with and without epilepsy: (1) epilepsy experience/impact and accommodation; (2) safety precautions; (3) concern about seizures; (4) social connections and acceptance; (5) parent and family support; (6) intrapersonal self-regulation, motivation and adaptation; (7) health benefits; and (8) factors in common with youth in general. Each theme is illustrated by quotes from the focus group discussions. Some of the quotes illustrate more than one theme.

3.1. Theme one: epilepsy experience/impact and accommodations

Both caregivers and youth expressed the importance of making accommodations to ensure the YPE could engage in PA. This included caregivers’ availability during PA and aligning caregivers’ selection of activities to their child’s skill sets. For instance, as this 18-year-old female participant shared: “I constantly have seizures, like at gym at school, and I’ve had three in the pool. And I just sink…my parents would have to sit outside of the pool while I swam…but sometimes they couldn’t.” (also theme 3.2).

Two parents expressed the importance of making accommodations for meaningful engagement: “She played regular ice hockey…then after her surgery…she would drop the stick. She couldn’t pick it up with her hand. So, I said, well, they can’t stop the game every time you drop your stick. So, we found sled hockey for her…And she’s really good at it” (mother of 13-year-old female).

“(We bought) an adult tricycle so that she could ride her bike after her surgery…She couldn’t move her right side. So, she needs a special kind of pedal.” (mother of 14-year-old female) (also theme 3.5).

However, some parents did recognize that PA is a lower priority than managing their child’s condition via anti-seizure medication and academic responsibilities, “managing her medications and everything else related to [going to university] is going to be…the biggest challenge rather than actually being active.” (mother of 17-year-old female).

3.2. Theme two: safety precautions

Although caregivers highlighted the importance of accommodations for facilitating PA engagement, it was also evident that accommodations help with safe participation: “…as a parent, you’re trying to protect them so much so that you’re almost putting them behind the 8 ball like their whole childhood…there’s always other things as parents…ways we can accommodate them so they can do some of the same activities in a safer environment” (mother of 13-year-old female). (also relates to themes 3.1.,3.3.).

Caregivers described that employing safety measures such as communication devices made them more comfortable encouraging their child’s PA participation.

“Having him have a cellphone…It’s just so much easier to know that when he goes out there, he can text me anytime, just in case he does have a seizure…So that’s really taken a lot of the stress off. And just letting him go out with friends.” (mother of 15-year-old male) (applies also to theme 3.5.).

The mother of an 18-year-old female talked about a creative adaptation to her daughter’s swim uniform that helped improve safety parameters during swimming participation, in particular: “We always had S. wear really bright swim caps so that we could track her in the pool, especially during swim meets when there’s so many people… so that [she] could be monitored by lifeguards really closely.” (also theme 3.5.)

We also found that parents described schools having concerns about whether a YPE can safely participate in PA, which posed an additional barrier to PA engagement: “In a way too, it affected her at school…because you have to inform the school about her conditions…that’s why it affected her during gym time where the teachers were…not allowing her to…get involved in…physical activities.” (mother of 14-year-old female). (also theme 3.8.).

3.3. Theme three: concern about seizures and the challenges of letting these thoughts go away

Consistent with previous literature (Pimentel et al, 2015), concerns were identified about PA triggering seizures, although just by caregivers in the present study. For example, the mother of a 13-year-old female said, “What if she has a night where she doesn’t sleep well because she’s so wound up from, you know, playing at an activity right before bed…it was mostly mom and dad who are worried about what this might trigger for her.”

Whereas the previous example highlights the worries of a seizure occurring after PA participation, other parents conveyed their concerns about what may happen if a seizure occurs during PA participation. The father of an 18-year-old female expressed these feelings clearly: “[Swimming] comes at a risk and as a parent [it] was incredibly hard to wrap your head around that…my wife [and] I were always on deck. I…pulled her out myself twice when a seizure occurred. So, it’s how do you keep that balance?” (also themes 3.2.,3.4.)

Caregivers also consistently expressed concerns that being diagnosed with epilepsy would prevent their child from being able to participate in sports and PA.

“There were many years he couldn’t do a lot of things, because of the epilepsy, and I think loving concerned parents have to be aware of what they’re saying sometimes to their kids. ‘Don’t do that. Be careful, don’t do this’, because you’re told not to do it out of total concern for your child, but when you say don’t do that you just start putting barriers up to them and…it leads to lack of activity because they are told not to do that but out of love it can have a negative effect…putting them in a box of ‘don’t do’ stops them. Be there but don’t stop them.” (father of 14-year-old male) (also themes #3.2.,3.3.)

“When J was first diagnosed…she was very concerned, as were we, that she wouldn’t be able to play sports anymore” (mother of 15-year-old female).

3.4. Theme four: the power and pressures of peers: social connections and acceptance

YPE acknowledged in the context of discussing PA that connecting with peers who also have epilepsy is a very powerful motivator that can open the door for PA opportunities.
“I don’t like really talking about [epilepsy]... to like other people that don’t really understand it. I’d like to find someone... maybe that has epilepsy... or they just have seizures or whatever. Um, so like we could talk about it and like would have something in common and then maybe we could like build a friendship or something. Can’t it’s kind of hard to explain to someone... what it’s like when they don’t like really understand it... I think it would just make it easier and stuff.” (15-year-old female)

“I wish I had met you guys earlier. So then, you know, we could have talked and challenged each other. Because none of my friends know what it’s like to have epilepsy.... So to have someone that was in the same situation as I was, that would have been an awesome help as well.” (17-year-old female)

Peers were also identified as creating some additional pressures or barriers to their PA. This issue was most pronounced among peers who were not aware of YPE’s condition as outlined by a 17-year-old female: “It affected my team a lot. Sometimes I’d have two or three [seizures] a game and my team thought I was retarded.” Many YPE felt as though having epilepsy negatively affected their acceptance among peers, which was very distressing: “She felt like she wasn’t accepted by those other students who just saw ... all these physical... ailments, problems and issues. Those are her words, not mine.” (mother of 14-year-old female).

3.5. Theme five: parent and family support

YPE identified that caregiver availability was important to their participation. An 18-year-old female participant shared, “I constantly have seizures, like at gym at school, and I’ve had three in the pool. And I just sink...my parents would have to sit outside of the pool while I swam...but sometimes they couldn’t.” (also theme 3.2.).

Caregivers found volunteering to coach for their child’s sports team enabled greater participation. This was, however, noted as both a facilitator and a challenge to navigate expectations among players, parents, and buffer any response when her daughter was unable to play: “I needed to coach to make sure that she could play [soccer]. But it was super difficult as a coach trying to make excuses why our fantastic goalie isn’t here again... (mother of 17-year-old female). (also theme 3.2.).

Caregivers and YPE both noted the importance of the family’s role in supporting, modelling, and encouraging PA. For instance, the father of a 14-year-old male stated, “I think you have to be a role model for our kids in order for them to know that that’s something that is normal and good to do... if they see you being active and you are active with them then that leads to an active lifestyle for later life for them.” This view was reiterated by a 17-year-old female, “It’s a lot easier for a kid that their whole family gets into it. Just really hard when a kid is trying to be physically active, when their family’s being unhealthy.”

3.6. Theme six: intrapersonal self-regulation, motivation, and adaptation

Several YPE identified apps and activity trackers as motivators for engaging in PA, while also helping them to self-regulate their behaviour. “I had sort of a big problem with keeping myself consistent. I found the Fitbit...you just go on the app and see your progress. It was a big motivation for me. Whereas if I didn’t have my Fitbit on, I’d find myself really slacking off.” (17-year-old female).

“There are challenges that you can complete, like, for your weekly goal, or like, if you challenge one of your friends that has a Fitbit. And you’ll get stickers or badges...it’s really cool.” (17-year-old female).

Beyond using apps for motivation, YPE also noted the positive impacts of exercise on stress reduction and improving their body image. A 17-year-old female said, “I find that working out lessens my stress... I usually find that I’m eating healthier because I want results”.

“The Fitbit study...made her realize that exercise makes her feel good... She feels better, like I guess just a better state of mind, I suppose.” (mother of 13 year-old-female) (also theme 3.7.)

“...encourage teens or kids with epilepsy, to start tracking, like the calories that they’re like getting in their bodies.when I started doing that, I realized, “Wow, I’m a really unhealthy child”. And that really encouraged me to start eating better and to start exercising, so I could burn off those calories...I started using my Fitness Pal. And it was like a really big motivator for me.” (17-year-old female)

3.7. Theme seven: secular forces – sedentary behavior may compete with the health benefits of PA

Caregivers identified the benefits/facilitators of advancing in both age and maturity to recognize benefits of PA: “I’m not sure how much is tied to their maturity, but...if you look back a number of years, I would say that [physical activity] is not tied to competitiveness at all, it’s tied to how they feel when they’re doing it” (father of 18-year-old female) (also theme 3.5.).

“They just have to be more aware of being active because their lifestyles nowadays are based on sitting around devices. That’s basically the way the school systems are set up all their homework and everything is on these devices. So, they’re almost motivated to be inactive with their lifestyle that’s being pushed from the school system.” (father of 15-year-old female).

Although peers may help draw some YPE to engage in PA, sedentary pursuits that they engage in with friends such as driving home from school present a competing interest that could decrease PA in adolescence: “All my friends drive. I’m learning to drive. So that’s a huge thing. I don’t want to walk home anymore, because all my friends drive.” (17-year-old female).

3.8. Theme eight: key factors in common with youth in general

Participants also identified several important factors that affect youth with and without epilepsy, as this father of an 18-year-old female recognized that ‘one size does not fit all’; “…[the study] was a good opportunity for promoting exercise, without necessarily promoting the organised activities. We’re not a sporting family, it simply wasn’t something that our lifestyle was supportive of. And so being able to get out and do something as simple and as low barrier to entry as walking was really good to see that encouragement.”

Another recurrent reflection was matching the individual personality to the types of activities they engage in and being much more drawn to independent activities as this 17-year-old female reported: “I’m kind of more of the shy kind of person. So, I prefer doing things on my own. I’m not really into sports, because I’m afraid that people are always watching me kind of thing. So, I like to do it on my own.”

However, other YPE discussed social support and social settings as critical for engaging in PA, and highlighted that it may simply matter who they would be participating with: “I prefer to do [physical activity] in a group because then others can keep you accountable... I think it’s harder to do it on your own because then you find yourself slacking off, and no one except for yourself is keeping you accountable. And that takes a lot of will-power” (17-year-old female).

Also deliberated was the value of matching personalities as a mother of an 18-year-old female explained: “I think that she’s a little bit socially awkward... she gets along with everyone. She’s just not a cool kid, you know... So I think that a lot of the activities that she’s involved with have to do with who’s actually participating.”

The focus groups’ discussions during the COVID-19 pandemic led us understand that the Covid pandemic may have posed greater challenges for this population, who often have greater limitations from the start and identified decreasing opportunities for social support, participation, and engagement: “I think for my son, one of the main things that was closed down during COVID, was the playground...They weren’t allowed to go there. And there were people there telling them ‘We’re going to call [the police]’...” (mother of 14-year-old male).
4. Discussion

4.1. We and others have identified the need for more research on PA in the pediatric epilepsy population, given the few studies that have exclusively focussed on YPE (Johnson et al., 2020)

The purpose of this study was to identify barriers and facilitators of PA engagement in YPE with the intent to offer advocates, providers, educators, and people working in sport and recreation facilities recommendations on how to support PA in YPE. Understanding the experiences and attitudes concerning PA may allow professionals to address fears and reassure both YPE and their families and friends (Johnson et al., 2020). Clinicians need to ensure to address PA-related issues with their epilepsy population.

Undeniably, the focus group interaction provided rich insights into the facilitators and challenges to PA, and the everyday experiences of these families. Although we planned on reporting facilitators and challenges to participation in PA that are relative unique to YPE, we also identified the need to share a few significant factors that are common with youth in general. We invited YPE who had active epilepsy during the interventional study (Brown et al., 2019) to participate in the current focus group discussions. Some of these participants still had active epilepsy and were taking medications, whereas others were seizure-free and were self-managing in other ways. This diversity allowed us to access a broad range of perspectives and insight into the lived experiences of YPE and their caregivers. Overall, the focus-group technique proved a valuable opportunity for YPE and their caregivers to share their lives and bounce ideas and self-management strategies off one another. Overall, there were many similar themes among YPE and their caregivers, as both shared similar perspectives on the impact of having epilepsy on PA. However, different themes were emphasized between YWE and their caregivers with respect to safety, barriers to PA, and the effect of epilepsy on youth growth and development.

4.2. Despite addressing a critical knowledge gap, limitations of the present study should be acknowledged

The COVID-19 pandemic presented challenges for recruitment despite the study being conducted online. Potential participants were likely occupied with transitioning to the circumstances with which they were presented. As a result, we were unable to recruit enough males YPE to conduct a focus group, and therefore were not able to capture directly the experiences and attitudes concerning PA may allow professionals to address fears and reassure both YPE and their families and friends (Johnson et al., 2020). Clinicians need to ensure to address PA-related issues with their epilepsy population.

4.3. We were excited to learn several important actionable lessons that can be applied by service providers and other professional

4.3.1. YPE are interested in physical activity that matches their interests and personal preference for individual or organized group/team activities

Temperament, personality, and situational factors may have children/youth gravitate to one form of activity over another. This observation is consistent with person-centered services that take account of the individuality of each person. While some youth articulated their perceived value of scheduled and organized group events, others expressed lack of interest in any PA. It is therefore important for health care professionals to consider condition-specific preferences and barriers that need to be addressed to enable YPE to engage in safe and meaningful PA opportunities as highlighted by the ILAE Task Force on Sports and Epilepsy (Capovilla et al., 2016).

4.3.2. It is important to seek to understand worries/concerns of caregivers and children/youth, as worries can contribute to a child’s anxiety in participating in activities

Parents reported feeling anxious and/or worried that participating in an activity might trigger a seizure or create challenges if their child has one while participating (e.g., while swimming, going for a run independently, riding a bike on a busy street). This can influence their choice of activities or limit a child’s participation to when they have a caregiver or partner be active with them (Webster, 2019).

The burden of pondering if there was a connection to their child’s epilepsy because of something they had done wrong was noted by mothers of both males and females. They also articulated how some limits set may not actually be a physical issue, but “more kind of psychological limits.” Spending time with caregivers to understand and address their concerns and worries may support them in reducing self-blame, lessen the transference of anxiety to their child, and promote finding the right situation/activity/environment for their child to participate in.

There were also reports of feeling “there was always that kind of threat of his seizure hanging over us”. Youth also had some concerns about what might happen by participating in an activity. Exploring what is important to youth, partnering with them about their specific worries/concerns and discussing approaches that can be used in management can support the development of care plans and strategies together.

4.3.3. Youth reported valuing caregivers/family also being active as a motivator for their PA and keeping them safe

Health care providers are encouraged to discuss the value of modelling and actively engaging in activity with children/youth as previously reported (Trost et al., 2003; Wilk et al., 2018). Parent support for physical activity may be even more imperative for young people with chronic health conditions and disabilities (Brown et al., 2020).

4.3.4. Focus on self-regulation, motivation and adaptation

Youth showed greater interest in using activity trackers/Apps to monitor their activity, see their progress and set goals than when they were younger. Body image was also noted as a motivator. Providers and others should consider the role of child/adolescent development and milestones within their clients and inquire about the things they are navigating on a daily basis so recommendations align with and support needs. Developing interventions that support autonomous motivation for physical activity may foster increased engagement in self-regulation techniques and positively affect physical activity behavior (Nurmi et al., 2016).

4.3.5. Explore who may be most helpful for youth to connect with

Youth reported an interest in connecting with other youth with epilepsy. Mothers also reported connection as a valuable consideration whether in person or virtually both for themselves and their children. Health professionals are encouraged to explore interest in opportunities for patients to connect and collaborate with allied health to create such networks and mechanisms for connection.

4.3.6. It is helpful to remind youth and caregivers that physical activity does not have to be organized sports, or those with a cost

It is therefore important for providers to understand the environment of the child/youth with epilepsy and connect goals that are consistent with their values and resources. For example, walking can be a safe alternative to organized sport (Gordon et al., 2010).

Some of our findings were consistent with the general population of teens who need to balance school (which is quite a sedentary experience), homework and to achieve academic success as well as balancing part-time jobs and social activities with friends, which causes further time constraints to fit in PA.
5. Conclusions

‘Going to the source’ allowed us to acquire a direct understanding of the diverse personal, developmental, and social factors that may help parents and professionals to design and target individually tailored interventions to help YPE adopt, self-manage and sustain a healthy lifestyle. Multiple areas of a youth’s life with epilepsy, including family support and social acceptance, impact their motivation to be physically active, as do a range of facilitators and challenges to PA. By understanding these lived experiences, professionals can better support YPE and their caregivers and help them maintain a healthy lifestyle.

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Conflict of interest

The authors have no conflict of interest to declare.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.eplepsyres.2022.107035.

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