Epilepsy & Behavior 172 (2025) 110681

Contents lists available at ScienceDirect

Epilepsy & Behavior

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

Research Paper

"I don't know enough about epilepsy": experiences and perspectives of sport and fitness professionals on training adults with epilepsy

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ARTICLE INFO

Keywords:
Epilepsy
Sport and fitness professionals
Coach
Personal trainer
Stigma
Qualitative
Exercise

ABSTRACT

Exercising with a physical disability has seen a surge in research, particularly focused on the education of coaches. However, epilepsy is notably absent from this recent advancement, despite its high prevalence. In response to this omission, we aimed to investigate what those working in the fitness industry know about the condition, previous experience they have had in training people with epilepsy, and what would they want to know more about to confidently train people with epilepsy in the future. We conducted semi-structured interviews with 11 participants (coaches, personal trainers, and fitness instructors) to explore their experiences and perspectives of training adults with epilepsy. Using reflexive thematic analysis, our results foreground, on the one hand, a common lack of knowledge, nervousness and fear; yet, on the other, the desire to learn how to be more inclusive. One new barrier found for training people with epilepsy was the costly nature of specialist insurance. In light of these findings, further research to develop more inclusive methods of education, promoting the benefits of exercise for people with epilepsy, are needed within the sport and fitness profession.

1. Introduction

Epilepsy is a hidden neurological disorder that does not fit neatly within the concept of a physical disability [1]. Moreover, labelling it as a physical disability is often challenged by those with the condition itself [2–5]. One non-medical based approach shown to aid people with epilepsy (PWE) is exercise. Exercise can improve overall physical and mental health for PWE, resulting in higher quality of life (QOL) [6–8]. However, a common barrier to exercise for PWE is stigmatised views and resultant exclusion by sport and fitness professionals [3,4,9]. Continued experiences of stigma in an exercise environment can also cause PWE to not disclose that they have epilepsy because of the fear that they may not be able to partake as they desired [3,4,9].

The ability to exercise with epilepsy differs from those with a visible physical disability. For example, the physical barriers and adaptations needed to exercise are not consistently the same for individuals with disabilities such as cerebral palsy or those needing a wheelchair [10]. Furthermore, although further education is provided specifically to support coaches of those with visible conditions or disabilities [11,12], there is a lack of specific further education for coaches about epilepsy. Moreover, although there has been a recent surge in research exploring the experiences, perspectives and knowledge of being a coach of disabled athletes and how they have felt during the learning process [11,13,14], there has been limited research exploring such topics with fitness instructors or personal trainers.

To bridge this gap, Obrusnikova, Cavalier, and Blair-McKinsey [15] explored the experience of personal trainers training individuals with intellectual disabilities. Results showed trainers felt positives and negatives through working with this specialised population. Positives included clients' improved self-confidence and self-efficacy, which also led to personal trainers being more fulfilled in their position. Negatives included trainers not knowing how to help their client and needing to devote extra time and work to training. This research pinpoints that there is still a need of further time and education required to aid those with a disability to exercise safely and more regularly with the support of a personal trainer [15].

Despite some research on the interaction between those with physical disabilities and coaches and fitness professionals, one type of disability is notably under-researched: namely, those which are hidden but can suddenly become visible and physically debilitating, such as epilepsy. This is important because PWE have a low physical activity and exercise rate [16], but it remains unclear how can we help them further if they are often excluded or too fearful to join teams or gyms, in part due to the attitudes and behaviour of coaches, fitness instructors and trainers

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https://doi.org/10.1016/j.yebeh.2025.110681
Received 22 July 2025; Received in revised form 22 August 2025; Accepted 24 August 2025

[3,4].

1.1. Research aim and objectives

The aim of this research is to investigate the experiences and perceptions of coaches, personal trainers, and fitness instructors on training PWE. Within this aim, there are three research objectives: (i) understand what coaches and fitness professionals know about epilepsy, (ii) understand existing exercise provision for the condition, and (iii) obtain first-person perspective on how to increase knowledge about epilepsy for coaches and fitness professionals, in order to enable PWE to exercise more regularly with their guidance.

2. Methods

2.1. Participants

Following institutional ethical approval, purposive and snowball sampling were used to recruit participants through university sports teams and gym, social media (e.g., Facebook), and contacting various leisure centres in the * region. Inclusion criteria were that they needed to currently be employed or have been employed as a coach, personal trainer, or fitness instructor of adults (18 years of age or older). They did not need any knowledge of epilepsy, nor experience of training an individual with the condition.

Upon extensive advertising of the study (18 months) and discussions of what the study entails, 11 participants took part in the study (see Table 1 for demographics). There was a variation in sports coached (e.g. baseball, football, American football) as well as exercise type (e.g. Zumba instructor, yoga instructor). Two participants had epilepsy and there were two participants from the United States (US). Participants from the US trained and currently worked there. All names used are pseudonyms to maintain confidentiality.

2.2. Procedure

Individual semi-structured interviews were conducted to allow for key topics to be discussed, but also to allow for a range of flexibility to obtain new insights [17]. Ethical considerations were put in place throughout as the first author is a PWE and we thought this might create a feeling of nervousness or unease from the participants who did not know about the condition. Therefore, we aimed to have the participants who did not have epilepsy or did not know anything about the condition be interviewed by the second author. When he was unable to conduct an interview due to time restraints, the lead author conducted the interview. This led to the second author conducting the first four interviews and the first author conducting the next seven. Disclosure of her condition was always ethically provided to the participants prior to the start of arranging the interview and if they felt comfortable to take part, they had the opportunity to ask questions prior to recording. If they felt unease or did not want to take part in the interview, they were allowed to withdraw.

All interviews were conducted online. This allowed for reaching non-local participants, but did decrease the element of comfort or increased rapport that can be felt when conducted in-person [18]. All interviews were audio-recorded and ranged in time from 24 min to 1 h and 11 min. Main interview topics included participants' background as a sport and/or fitness professional, their knowledge of epilepsy, experiences of training someone with epilepsy, and perceptions of how it would be to train a PWE. We finished by investigating what they would want to know about epilepsy and how this could be achieved in practice. Sample questions are found in Fig. 1.

Table 1
Participant demographics.

Name	Gender	Occupation	Location
Alan	Male	Football Coach	England
Jane	Female	Personal Trainer	United States
Amy	Female	Fitness instructor	England
Max	Male	American Football Coach	England
Mike*	Male	Baseball coach, fitness instructor	England
Anne	Female	Personal Trainer	United States
George	Male	Personal Trainer	England
Liz	Female	Personal Trainer	England
Cindy	Female	Fitness Instructor	England
Emily	Female	Fitness Instructor	England
Roger*	Male	Rowing coach	England

*Person with epilepsy.

2.3. Data analysis

Reflective thematic analysis [19] was used to develop the main and related themes, as well as to be consciously aware of the need for our own position and thoughts throughout. After transcription, the authors separately familiarised themselves with the first two transcripts by reading and re-reading the transcripts. Next, each author separately coded the transcripts. Upon finishing the coding, we discussed our mutual thoughts of our analyses. This led to further shared reading and subsequent coding of the remainder of the transcripts. Once all the initial coding was completed, the first author identified themes and this was then discussed with the second author to review and refine these themes. Lastly, the final themes were named and defined. Throughout the process of analysis, reflection was conducted prior to and during analysis by the first author. This helped to refine the themes as well as become more aware of the personal connection that could influence the data findings.

2.4. Reflexivity and rigour

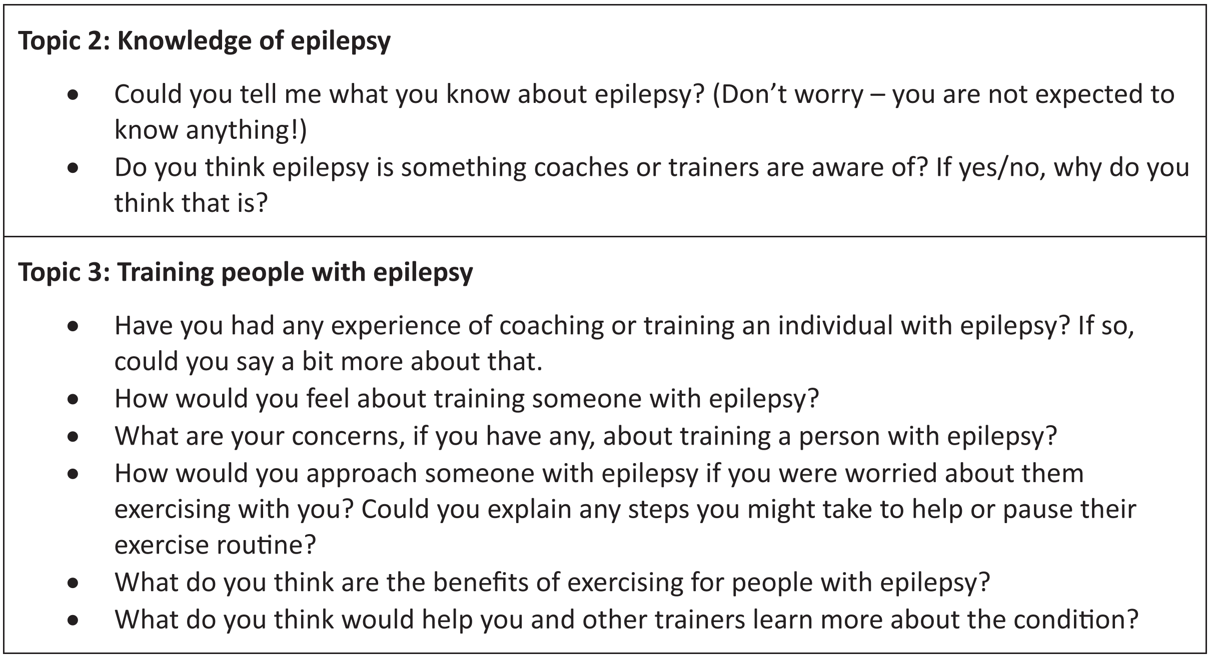
To ensure quality and acknowledge subjectivity within data collection as well as analysis, reflexivity was conducted throughout the interview and analysis process [19]. This allowed for personal preconceptions to be made visible and enhanced the rigour of this study [20]. Through the use of a research diary, prior to and after conducting interviews, the first author wrote out her own feelings of fear or worry of her influence over the participants. This ranged from the insecurity of having to describe her seizures in front of the participants to the worry of facial reactions when a participant might state something that was found insulting to her. During analysis, a critical dialogue was held between co-authors, aiding the analysis process through discussions of interpretation, code and theme labelling, as well as how language was seen as quite a key factor within this process [21,22].

3. Results

Three main themes of *knowledge of epilepsy*, *feelings and perceptions of training PWE*, and *learning strategies* were identified. Within each main theme, various subthemes present a clearer picture of the lack of knowledge about the condition, worry about training PWE, financial burdens involved in training PWE, and the desire to learn more to become more inclusive. Fig. 2 shows the thematic map of our findings.

3.1. Knowledge of epilepsy

The interest in education, in various forms, was seen as a catalyst towards a positive and confident desire to train PWE. This contrasted with those who were not aware and never consciously thought that someone they have trained or currently are training could have the condition. Within this theme we identified four sub-themes: (i) experiencing epilepsy, (ii) lack of knowledge, (iii) wanting to know more, and (iv) not looking for it.



Topic 2: Knowledge of epilepsy

- Could you tell me what you know about epilepsy? (Don't worry – you are not expected to know anything!)
- Do you think epilepsy is something coaches or trainers are aware of? If yes/no, why do you think that is?

Topic 3: Training people with epilepsy

- Have you had any experience of coaching or training an individual with epilepsy? If so, could you say a bit more about that.
- How would you feel about training someone with epilepsy?
- What are your concerns, if you have any, about training a person with epilepsy?
- How would you approach someone with epilepsy if you were worried about them exercising with you? Could you explain any steps you might take to help or pause their exercise routine?
- What do you think are the benefits of exercising for people with epilepsy?
- What do you think would help you and other trainers learn more about the condition?

Fig. 1. Example of interview questions.

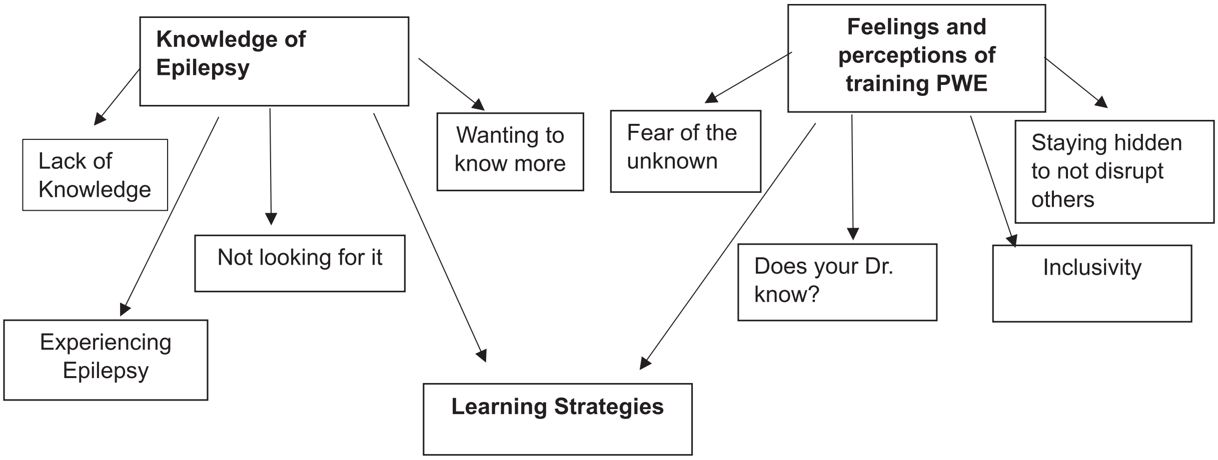


Fig. 2. Thematic map.

3.1.1. *Experiencing epilepsy*

Although most participants did not have direct experience of epilepsy, our sample included two participants who have the condition and one who is in a relationship with one of those participants. One participant (Roger) had tonic-clonic seizures and although seizure free for many years, still had memories of riding his bike when a seizure occurred, noting that "most of the real harm that I've had… during my attacks (seizure) are between having the attack (seizure) and hitting the floor… I've actually had one on a bike and I just keeled over, hit the kerb". Roger also had the experience of being a rowing coach of a person with epilepsy. In discussing this further, he noted that not only did his athlete's consultant say that "her [seizures are].. inhibited by exercise", but also "my observations with the ones that she's had tend to back that up". (Roger). Through his desire and will to overturn unfair sporting guidelines that restrict the participation of PWE, he was able to overturn some British rowing restrictions that did not pertain to certain athletes:

> The reason why I think that's [Rowing guidelines] a bit extreme is that… it covers so many bases, so many other types of epilepsy and Nancy's (pseudonym), is unusual, well it's not like mine in that um…, exercise inhibits it. She's never had a seizure during exercise. Quite frankly, rowing is quite… strenuous, so it is very unlikely that she'd have one on a boat. (Roger)

Roger's description of Nancy's epilepsy being unusual because 'exercise inhibits her seizures' highlights that as a person with epilepsy and a coach, he is unaware of research showing the positive benefits exercise can have for PWE.

Another participant (Mike) has uncontrolled epilepsy (tonic-clonic seizures) and his partner (Amy) reflected on her reaction to them, noting that, "I have the theory from first aid courses of what to do and how to deal with them but obviously it was shocking the first time that, you know, I had to deal with it" (Amy). Amy's description does indicate that a first aid course does not provide adequate direct experience of seizures. The shock that resulted created uncertainty on how to deal with a seizure, should it occur. This uncertainty was manifest in most participants' accounts, with many seeming not quite sure how to describe their feelings and not wanting to say something they perceived as 'wrong'.

3.1.2. Lack of knowledge

Few participants had direct experience of epilepsy or training PWE. Moreover, when asked about the benefits of exercise for epilepsy, most participants gave very general responses. For example, Jane noted that, "The benefits would be probably the same as exercising for anyone", and George said, "You've got the generic benefits of weight loss, feeling better and self-esteem. So I'd say as a general population, it's basically very similar to [the] general population". He further thought that exercise would give people with epilepsy "a greater awareness of your limbs and the strength associated with that". This focus on body control was also proposed by Liz, who foreground potential benefits such as "flexibility, mobility… [and] having like control over your body". Overall, describing it as "the same as exercising for anyone" (Jane) was a common response, revealing the specific neurological and psychosocial impact of exercise for epilepsy was not commonly perceived.

In describing what seizures look like, most participants described a tonic-clonic seizure, highlighting a lack of knowledge of the variety of seizures. However, others did state that there could be seizures they were not aware of, noting that, "sometimes seizures can be minimal [and] they can look much more scary than they are to the person that it's happening to" (Cindy).

The consistent lack of knowledge as to what epilepsy entails and how to help someone if they have a seizure also manifested in the lack of training most participants received. Notably, many participants reported that, if covered at all, epilepsy was only briefly covered in first aid courses:

> I did first aid (at) competitions, so I learnt about epilepsy at that point. In terms of you know moving items away if someone goes into a fit (seizure) and not having any obstruction in the mouth and trying to, if you can, get them into the recovery position and that sort of thing. But that's about- you know, I did say at the beginning, my knowledge was minimal and that is as far as I went with it. (Max)
>
> I've always put diabetes, epilepsy, and that kind of thing into the same consideration bracket, which is probably massively offensive. (George)
>
> There were some conditions that were just very quickly touched on in my … Level 4 Neurological last year… I got my notes out to see if there was anything in there and there wasn't. (Liz)

Expressing the lack of knowledge about the condition in conjunction with not being educated about it within a sport and exercise context, the general naivety about epilepsy was quite common amongst our participants.

3.1.3. Wanting to know more

Through describing what they knew about the condition, a common sub-theme identified was of wanting to know more. However, this desire did vary as some participants wondered if it would be necessary for what they were doing:

> Would I want to know more about it? I'm pausing because on the intellectual side I would say yes, but then on the practical side I'm thinking how much would it affect how I teach? And I think, as long as the person feels able-bodied enough to do most of the things that we do, then honestly, I probably would not be interested in knowing more details. (Cindy)

Looking at it in a more practical way, Max said that, "I would rather… have a session… about medical conditions you might encounter along the way and what it is, what are the essential things you ought to know, and where can you get further guidance". Another participant, Amy, foreground the importance of gaining knowledge through first aid courses, noting that: "Absolutely [there] should be more awareness… about it, because the people need to know how to possibly help them to not hurt themselves even worse".

In addition to the focus on gaining knowledge and awareness, the physical impact of having epilepsy in relation to taking part in sports or exercise was discussed by one of the yoga instructors:

> I would have to read some books on epilepsy. I would have to because, gosh. Yes, I would definitely like to know more, especially the circulation. Can they go upside down? Suddenly, can they stand up? Because yoga is a lot up and down. How long can they be upside down? So, definitely that would be a very expansive reading and notes-making. (Emily)

Interestingly, one of the participants who had uncontrolled epilepsy was not keen on learning more about the condition nor thought it should be widely discussed in sport and exercise, stating that he "do(es) not research a lot", and that "if something happens, it's going to happen, it's nothing that we can control" (Mike).

3.1.4. Not looking for it

In tension with the desire to know more, participants also stated that epilepsy was not something they consciously looked for, reinforcing the depiction of epilepsy as a hidden disorder. Many participants discussed this in relation to what type of individual would be referred to them for health reasons, "You don't really look for- I don't know if epilepsy, neurological, but mostly you're looking for heart conditions" (Anne). Whereas others simply noted that it was not something that they had really ever considered:

> It's just not something we tend to see, or that I've seen. I mean, I can only speak for myself. Not something that I- I tend to see in a sporting environment. (Alan)
>
> Because I'll be honest before you wrote to me and asked if I'd be involved in the study I had not considered- I mean I don't know now, do I have any players on either of my two teams? I deal with the University, about 65 players and the same number at the * [team name], so I'm dealing with about 130 players during the course of the year, so my chances are that I've got one. (Max)

Moreover, in stating that he's "got one", one could argue that this shows that Max is, on some level, aware of the prevalence of epilepsy, but it can also be conceived as somewhat dehumanising, supporting the perception of epilepsy as something abnormal or set apart.

3.2. Feelings and perceptions of training people with epilepsy

The second main theme revealed participants' perceptions on training PWE. Four key sub-themes emerged: (i) does your doctor know?, (ii) staying hidden to not disrupt others, (iii) fear of the unknown, and (iv) inclusivity.

3.2.1. Does your doctor know?

One key finding, particularly amongst personal trainers and fitness instructors, was a concern about whether their insurance would cover training PWE. For example, George stated, "I think I'd check the insurance that I wasn't invalidating it too much" and that "a lot of the limitations come from what the insurance says you can do. So, if you've got the bog standard insurance, it basically says don't treat anybody unless they're completely clear on the PAR Q (Physical Activity Readiness Questionnaire)". This view culminated in the idea that "the more specialist you get, the more careful you need to be with the insurance", framing epilepsy as maybe too risky of a condition because of the resultant higher costs.

In line with this risk-averse attitude, some participants foreground the idea of transferring responsibility from themselves to a healthcare professional. Anne stated, "[if] their doctor said it's okay for them to work out and then you have them sign a waiver" and that they would ask the client "'does your doctor know that you're going to train?'" (Anne). However, another participant also noted that "we would need like a disclaimer, but we need that for everybody" (Liz), highlighting that the transfer of responsibility for health issues is a common move for coaches, trainers, and fitness instructors regarding all health conditions.

In addition to insurance-related concerns, other participants discussed feelings of insecurity, but also a desire to figure out ways in which they could encourage people with epilepsy to be open with them, to mitigate safety issues:

> If someone told me they had epilepsy, I would honestly just be like, okay, what does that entail? Does that affect your workout? I would just talk to them about it. (Anne)
> I think it would just be that reassurance from the person, having that little bit of conversation with them. And I don't know enough about epilepsy, and I would feel I suppose a bit awkward to say, 'Well, just how bad are your fits?' (Cindy)

Safety was key for many participants. But, unlike instances above in which participants focussed on the insurance risks to themselves, other participants focused on what PWE thought. If they felt comfortable to exercise with them, that showed they could be comfortable too. For example, Liz noted that, "I just kind of work with the person. Yes, and I would just want to know that they were confident enough to work with me and build up that trust". Mike, one of the participants with epilepsy, further highlighted a desire to build a fellow person with epilepsy's confidence in regard to taking part in exercise, noting that, "I had one player… but she had to step back this year because of seizures. I talked to her a lot, I said to her, 'I have the same condition, let's keep going'''. Although ultimately unsuccessful in his aim to motivate his player, it clearly affected him and he was disappointed that showing himself as a fellow person with epilepsy and exerciser did not encourage her to continue.

3.2.2. *Staying hidden to not disrupt others*

As stated in the earlier sub-theme, *not looking for it*, epilepsy was rarely seen by the participants. However, the common notion of it being a stigmatised condition was revealed in one example from a participant, Cindy, who recalled that "at the beginning of the class [a client] came to me and introduced herself, and that she had epilepsy, and that it would be okay because she had been taking yoga for a long time". Cindy further explained that her client felt the need to "position herself towards the back of the room" to avoid "intruding" in case of a seizure. "And, you know, everything about her was normal so I began the class." On similar lines, Mike did always state that he felt the need not to disclose:

> No, if I'm coaching, for example, when I started with the university, I didn't talk about my condition to the players. The university knows because I have to fill out the questionnaire, and the form, and they know. I don't say that to my players or anything. (Mike)

When questioned upon why he would not want to tell his players, he said:

> In that group, for the university are teenagers and I don't want to see how they will react or not, so, I don't feel shame for myself…. (Mike)

The personal sense that he would feel shame revealing his condition does highlight epilepsy as a stigmatised condition in which a person with epilepsy does feel the need to stay hidden so they can be seen as 'normal'.

3.2.3. *Fear of the unknown*

The ongoing importance of safety concerns, present in much of the analysis, recurred in the sub-theme of fear of the unknown. This led to many participants being open about their worries, feeling of nervousness, or anxiety in training someone with epilepsy:

> Some of the classes do have strobe lighting, especially things like spinning and the HIIT class, they like the whole atmosphere. So, in a gym I'd be nervous about training somebody. (George)
> If I'm honest, it would be probably– as we sit here right now, if you've said, doing a session tonight, and there's a player with epilepsy in it, there would be a nervousness… It would be from a coach's point of view, I guess that fear of the unknown. (Alan)

Such fear of the unknown was even present for Roger, who as discussed previously, has experience of coaching a rower with epilepsy. In particular, although her seizures were not exercise-induced there was a still a pattern in her seizure frequency that would put him on edge: "With Nancy (pseudonym) it was almost like you've had the lightning strike yesterday, you've got almost three months clear, but once you've got past three months, you're getting really twitchy". However, although nervousness and a fear of the unknown were still prevalent, one participant, Jane, did think positively about ways to overcome it:

> I guess I would feel sort of nervous, just the same I would feel if any underlaying condition. But I think that if they told me that ahead of time and what to look for, what signs to look out for and maybe I could– whatever it was– I could monitor, like if they were doing a certain thing, you know, sit down, or stop this, or drink water, or whatever the thing was that would help them in that moment, that they can tell me ahead of time would be really helpful. Because then, I could just be more– I think I would be nervous at first, then I would start pushing them like normal, and then I would make sure to look out for the signs, constantly. (Jane)

This expression of speaking with the individual to learn more demonstrates a method of coping with the initial uncertainty and nerves. It further expresses a signal to PWE that being open can also aid their desire to exercise.

3.2.4. *Inclusivity*

Developing the previous point about ways in which to overcome issues of PWE, some participants prioritized the importance of making adaptions to training and being inclusive. For example, George noted that, "I think you would have to be careful training in the gym. But most gyms have got first aiders available. But I think the overall benefit would outweigh the risks". He further highlighted the importance of "if not work[ing] with a personal trainer, get[ting] advice as to what exercises are good". In this way, exercise routines can be adapted to fit in with particular clients. After all, "every exercise has got an alternative to it". (George).

The importance of an inclusive approach to training was also noted by other participants:

> I hope I would never put anyone at risk of hurting themselves or, you know, injury but at the same time we're all different and there are ways around training people. Yes, and I always try to be inclusive (Liz).
> I think probably, in my mind the important thing is to try not to treat them differently and try to include them. (Max)

Following on from Jane's comment about talking with PWE prior to beginning training, these opinions demonstrate that an inclusive approach was common and iterating, perhaps PWE should not be overly wary of disclosing their condition to their coach or fitness professional.

3.3. *Learning strategies*

The previous main themes of *knowledge of epilepsy*, and *feelings and perceptions of training PWE* highlight the challenges of training PWE, in particular the lack of knowledge available. This last main theme highlights some of the strategies by which participants thought this key issue could be overcome. Multiple methods of how best to learn about epilepsy and decrease nervousness in training PWE were proposed, including using internet searching, creating a guide, as well as making first-person stories and experiences more widely available. With respect to self-directed strategies, Jane, for example, stated that, "if I knew I had a client with epilepsy… I would ask them lots of questions and I would do my own research just like, probably like Google first of all… and just make sure I was as prepared as I could be".

Beyond self-directed strategies, integrating specialised education into existing training or first aid courses was an idea proposed by a number of participants:

> I think that the best time to talk about it is really at a first aid course. It also, come to think of it, should be on the teacher training list. (Cindy)
>
> I think if there… was a… training course online, just something sort of like some information booklet or short course, yes just giving us more details about the condition. Yes, I think that would be really useful. (Liz)

Although formal courses were a common strategy proposed by participants, learning from those who have the condition themselves was also considered important, highlighting the need for a variety of strategies to overcome the distinct lack of knowledge of training PWE:

> I think speaking to people who have epilepsy and understanding what actually happens [is important]. I just don't know enough about it. I've got this image of all epileptics just having seizures when lights go off and on quickly and that's it. But now I've worked with people with epilepsy, and I know it's not that, but I don't know what it is. I assume there are different levels of epilepsy as well. But it's one of those things I just don't know enough about it. (George)
>
> I think… it's those stories as opposed to having some kind of explanation, medical things. Just to hear a story, "This is what happened and this is how people responded." That kind of tends to, I think, for someone like me be more useful than knowing some kind of more scientific reasons why somebody's having a seizure and what kind of seizure it is, and what it's called. (Cindy)

4. Discussion

By exploring the knowledge and experiences of sport and fitness professionals about training PWE, this study allowed us to gain first hand insight into their current understanding and what further support is needed. Our results demonstrate a significant lack of knowledge about epilepsy and how exercise can affect PWE. This foregrounds the view that epilepsy is not a condition that sport and fitness professionals consciously consider within a sporting and exercise environment. As a consequence, a common fear and worry in training PWE has been identified; however, it also highlighted a desire among sport and fitness professionals to know more and henceforth, be more inclusive.

There were few participants whose knowledge of epilepsy led them to feel confident and able to coach or train PWE. Unlike general coach education in disability sport [11,22], participants stated that there was limited access to information on this topic. Furthermore, this limitation made participants feel nervous and worried if a person with epilepsy did want to train with them. Such emotional reactions accord with previous research highlighting the experiences of coaches and trainers of athletes with intellectual and physical disabilities [15,28]. For the few that felt comfortable training a person with epilepsy, this was because of their own personal experience of living with the condition. That being said, many did feel as though if they learned more about epilepsy, they would feel more able.

Another key theme ('Not looking for it') was that epilepsy was a condition rarely seen in a sporting or exercise environment. This could be drawn from two factors: (i) PWE are not disclosing their condition, or (ii) PWE are not taking part in exercise as much as individuals without epilepsy. Research shows lower numbers for PWE in regard to taking part in physical activity and exercise [16]. But research also shows that PWE's fears and nervousness to exercise can be the cause of such disengagement [2,3,4,9,24]. Furthermore, the concept of stigma can cause PWE to not disclose to a coach, trainer, or instructor [3,4].

As a hidden disorder, epilepsy maintains this 'fear of the unknown' and caused participants to be frightened about what could happen in a sport and fitness setting. Such themes have been previously demonstrated, but from the perspective of PWE who experienced this fear themselves [3,4,9,25]. The impact of the lack of education and the invisible and unpredictable nature of epilepsy caused this fear and subsequent worry. Research in non-exercise settings has found similar responses [26,27]. The link to stigma, because of the unknown and hidden elements, increases the chances of others feeling unease, but also causes PWE to not feel as though they should discuss their condition with their trainer, coach, or instructor [3,4,9]. One way in which this disconnect can be overcome is through educating trainers, coaches and instructors about the condition.

The topic of specialist insurance to train individuals was mentioned as a barrier to limit the willingness of fitness professionals to train PWE. Although many mentioned they desired to be more inclusive, insurance was a hindrance in regard to training PWE. Brought up throughout our interviews was how costly it could be to train a person with epilepsy. Although presented within our findings, this could not be found in previous research and sparks new insight into further barriers to exercise for PWE.

In discussing what learning strategies would help them feel more comfortable and confident training an individual with epilepsy, there was a variety of responses. These varied from adding information to existing first aid training courses, creating a basic learning booklet, and learning directly from PWE themselves. Although there were many suggestions, and some individuals favoured some over others, such strategies have been used and discussed in a similar way previously [10,11,23,28,29]. For example, formal education in the form of a course is a common approach, but it does not suit everyone [30]. However, learning through engaging with personal experiences also does not suit everyone [14]. The differing opinions as to what approach would best improve education about training PWE, highlight the difficulty in developing a comprehensive and consistent approach to education. As such, a range of approaches should be explored further, in order to inform more coaches and fitness professionals on the topic of exercising with epilepsy.

4.1. Limitations

This study does have limitations that prevent its transferability of the findings to a larger population. As there was a small sample size and only had participants from certain areas of the US and England, these findings cannot directly portray what occurs across the globe. Although there was a variance in sports coached, this does not mean that some coaches from sports not included could have more training or experience than the participants that took part.

In order to improve on these limitations, future studies should include a larger sample size, ensure a more diverse range of participants' experience, and further global locations. Additionally, to further examine these findings by testing their significance and generalizability, conducting quantitative research on this topic would be of interest.

5. Conclusion

Our findings suggest that sport and fitness professionals' knowledge and experience of epilepsy can be a significant barrier to exercise for PWE. There are thus many further educational and practical discussions to be had to ensure that PWE can be confident in disclosing their condition to a sport and fitness professional, and that their needs can be met. To further this necessity, our aim is to make information about epilepsy more available and accessible for sport and fitness professionals. Moreover, our findings show that sport and fitness professionals are keen to learn more about epilepsy and to be more inclusive, this suggests that our aim to improve education about training PWE is realistic. This gives us hope that future research can substantially improve the knowledge of this hidden condition within sport and exercise.

CRediT authorship contribution statement

Sarah S. Collard: Writing – review & editing, Writing – original draft, Visualization, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Doug Hardman:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation.

Declaration of competing interest

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

Data availability

Data will be made available on request.

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