

‘I’d rather you didn’t come’: The impact of stigma on exercising with epilepsy

Abstract

Epilepsy is a common but hidden disorder, leading to stigma in everyday life. Despite stigma being widely researched, little is known about the impact of stigma for people with epilepsy within a sports and exercise setting. Using constructionist grounded theory, we explored the barriers and adaptations to exercise for people with epilepsy. Three focus groups (2-3 participants per group) and three semi-structured interviews were conducted (11 participants total). Stigma negatively impacted joining team sports, running groups, and disclosure to others. The effect of stigma was reduced by educating others about epilepsy, thus creating more awareness and understanding.

Keywords: epilepsy, stigma, exercise, barrier, qualitative, disability

Introduction

Epilepsy is the fourth most common neurological disorder behind migraine, stroke, and Alzheimer’s disease (England et al., 2014). However, the lack of education about epilepsy, added to the impact of it being a hidden disorder, causes many people with epilepsy to feel misunderstood and stigmatized, and as a result, fear disclosure to others (Jacoby et al., 2005; Schneider and Conrad, 1980).

Defined as ‘an attribute that is deeply discrediting’ (Goffman, 1963: p.13), the concept of stigma is a common topic within epilepsy literature. In addition to Goffman’s (1963) description of social stigma, people with epilepsy’s experiences can also be depicted through Link and Phelan’s (2001) four components of stigma: distinguishing and labelling differences, associating human differences with negative attributes, a separation of ‘us’ from ‘them’, and status loss and discrimination. The physical manifestations of epilepsy can appear frightening to those who do not know what is occurring, and the lack of awareness of the condition continues to cause people with epilepsy to withdraw from social situations for fear of stigmatization (Baker et al., 1999; Fernandes et al., 2009; Troster, 1998).

Enacted and felt stigma are two theoretically distinctive forms of stigma (Scambler and Hopkins, 1986). Enacted stigma refers to the ‘discrimination against people with

epilepsy on the grounds of their perceived unacceptability or inferiority' (Scambler and Hopkins, 1986: p.33). Felt stigma, on the other hand, refers to the 'fear of enacted stigma, but also encompasses a feeling of shame associated with being epileptic' (Scambler and Hopkins, 1986: p.33). This may arise from personal comparisons between themselves and 'normal' society (Jacoby et al., 2004; Scambler and Hopkins, 1986). Within epilepsy research, overall quality of life, psychological health, and identity have been linked to the negative impact of stigma upon a person with epilepsy (Jacoby et al., 2005; Raty and Wilde-Larsson, 2011). However, within specific areas of one's life, e.g. partaking in sports and exercise, stigma has yet to be explored in depth.

Stigma and Exercising with Epilepsy

There is limited literature exploring stigma and exercise for people with epilepsy. Kaufman and Kaufman (2013) highlighted that many people do not disclose their epilepsy as they believe it would be a barrier to partaking in sports and/or exercise. Fear of disclosure was also shown in the case of a person with epilepsy who presented her feelings of running with epilepsy (see Scarfe and Marlow, 2015). Desiring not to be known as only 'the person with epilepsy', Scarfe and Marlow (2015) presented aspects of felt stigma for the fear of being 'discovered' as a person with epilepsy caused anxiety and a negative impact upon her identity. Furthering this research, Collard and Marlow (2016a) presented narrative research over the course of one year, exploring the psychosocial impact of four people exercising with epilepsy and providing first-hand insight into felt and enacted stigma for people with epilepsy. One example of felt stigma was the fear of a negative reaction as a result of disclosure of his/her epilepsy to a lifeguard prior to swimming, thus leading to non-disclosure. In another incident, enacted stigma was shown by one participant who stated, 'You can see a few people are worried by it and don't want to talk to me and don't want to be

next to me [in the gym]...’ (Collard and Marlow, 2016a: p. 203). Such examples of stigma are rarely reported within current epilepsy and exercise literature.

Methods

The findings here are the result of a wider exploration of the barriers to exercise for people with epilepsy and the current adaptation techniques used to exercise safely and confidently (Collard and Ellis-Hill, 2017). Assuming an epistemological position of subjectivism, we recognize that there is a dynamic relationship between the participants and researchers (Gardner et al., 2012). Choosing to analyse using constructionist grounded theory (CGT) (Charmaz 1990, Charmaz 2006), we as researchers are taking an active stance to discover connections between concepts and to provide a deeper understanding of how stigma is felt and enacted, with a view to considering how it can be reduced.

Recruitment

Following ethical approval from Bournemouth University, participants were recruited via Epilepsy Action a) support groups, b) newsletter, and c) website. Participant inclusion criteria were: 1) be clinically diagnosed with epilepsy, 2) 18 years of age or older, 3) have no other co-morbid conditions that could prevent exercise, and 4) live within a two hours travelling distance from Bournemouth, UK. The latter criterion of travelling distance was changed to no travel restrictions, to support the recruitment process.

Participants

There were 11 participants in total (seven females; four males) who took part in either a focus group (three focus groups; 2-3 participants per group) or a semi-structured interview (three interviews). Participants had varied seizure type and frequency (see table 1; Notes), with some experiencing seizures weekly and more than one seizure type, whilst one participant

had not had any seizures for a couple of years. However, all participants were on anti-epilepsy medication.

Physical activity levels and choice of activity also varied amongst the participants and depended on the frequency of seizures for the participants. In participants with frequent seizures, e.g. more than one seizure per month, participants exercised two to four times per week. For those who had more controlled seizures, e.g. one seizure every two months up to a couple of years seizure-free, exercise levels were more frequent (range: three to ten times per week). However, when a seizure occurred, this could drastically alter exercise frequency, ranging from cutting exercise completely for a week, or reducing frequency by at least 50% (for details, see Collard and Ellis-Hill, 2017). On average, participants exercised four times per week. Walking, running, and swimming were the most common activities.

Focus Groups, Video Conferencing and Individual Semi-structured Interviews

Data were created in three ways: a) in-person focus groups (two focus groups, taking place in a University interview room), b) videoconferencing focus group (one focus group) and c) videoconferencing individual semi-structured interviews (three interviews). It is recognised that different methods of data creation will create differing types of data (e.g., limited ability to view nonverbal communication as may be conveyed by the positions of his/her body, more sharing of sensitive topics) (Tuttas, 2015; Woodyatt et al., 2016) and this was taken into account in our analysis.

The focus groups and interviews were audio-recorded after written and verbal consent from the participants. For the focus group and interviews conducted using videoconferencing (see details below), the video capture was not recorded. A topic guide was used in order to explore the themes around barriers to exercise, adaptation methods, and benefits of exercise.

This sparked an open discussion of themes (e.g. related to stigma, exercise adherence, social support, etc.) that may be currently absent from research.

Focus Groups

Focus groups were the main method of choice as they create an atmosphere where participants are able to have a group conversation on a common topic (Folch-Lyon and Trost, 1981). As each participant had epilepsy, this provided an environment where sensitive topics were more easily discussed (van Teijlingen and Pitchforth, 2006). Throughout the focus group sessions, the first author (S.C.) was the sole researcher present and provided ‘active people management’ (van Teijlingen and Pitchforth, 2006: p .31), enabling quieter participants to contribute rather than the conversation being controlled by one or two more talkative individuals. All focus groups ran for 1 ½ to 2 hours.

Videoconferencing - Focus groups

The third focus group was held using videoconferencing technology, owing to the travel limitations of the participants. Videoconferencing provides access for a greater number of participants, thus encouraging higher levels of recruitment and allows the participants and researcher to view each other, thus also preserving the group dynamic (Tuttas, 2015; Woodyatt et al. 2016). As was done throughout the in-person focus groups, notes documenting body language (that could be seen), pauses, and subsequent questions were taken during the videoconferencing focus group.

Although videoconferencing allowed more participants to take part, there were also limitations. Limitations included an inhibited full reading of body language and the concern of privacy. Due to the participant being in their own homes, ground rules of using

headphones and limiting others (e.g. family members, friends) to be with them during the focus group or interviews were discussed prior to the start of the session to ensure privacy.

Videoconferencing - Interviews

Interviews were carried out with three individuals (all females) because they were unable to attend any of the times or dates for an additional videoconferencing focus group. These were scheduled at a time suitable for each participant and were conducted online in their home. As stated above, the ground rules were set in place prior to the start of the interview to decrease any possibility of resistance to the full discussion of feelings and experiences, owing to the presence of others. There were no marked differences with the quality of disclosure between the interviews and the focus groups. However, one difference may have resulted from the lack of other participants present to spark the conversation into other areas/topics. We will not know the full impact or difference, but these aspects were taken into consideration and could be one limitation.

Trust and Rapport

The building of trust and rapport prior to all focus groups and interviews was key in developing a strong comfort level for the participants to open up and share their experiences. The main methods of building trust and rapport were through conversations on the telephone, email, and in person/online. This was further developed through my (Sarah) availability to discuss the topic further outside of our interviews and/ or focus groups. Through my own openness of exercising with epilepsy, further trust and rapport was developed (Collard and Marlow, 2016a, 2016b).

Researcher Reflection

As a person with epilepsy, I was open and honest with the participants about my own experiences of exercising with epilepsy. In order to prevent my own experiences or emotional state from interrupting the focus groups and interviews, reflection was a key tool in maintaining emotional balance and researcher integrity. Reflection techniques used included discussions with the co-author, self-reflection, and memo writing (Collard and Marlow, 2016b, Collard and Ellis-Hill, 2017). Although we acknowledge the potential effect of my own experience upon the interviews and focus groups, there was also a benefit as it created an atmosphere of comfort and openness of the participants (Collard and Marlow, 2016a, 2016b). Conversations with my co-author allowed me to discuss possible concerns in regard to emotional connection with the participants.

Constructionist Grounded Theory

The focus groups and interviews were analysed by CGT in order to develop conceptual connections that could be explored further. As shown by Charmaz (1990), CGT uses multiple steps in developing the concepts and eventual theoretical framework. After the first focus group, initial coding began. This involved verbatim transcription followed by coding and the development of a mind map highlighting initial concepts and possible connections.

Supplementary questions for the next focus group or interview were then developed in order to clarify concepts and connections. Focused coding was conducted to refine the categories and themes, leading to the development of the core concepts. Lastly, questions on the themes and concepts that had emerged from the later focus groups and interviews were then asked via email to the earlier participants in order to develop the theory further. In the analysis of the overall theory, stigma was identified as one main category and was shown to have core connections as a barrier to exercise.

Results

As a common barrier to exercise, felt and enacted stigma negatively impacted the exercise routine and experience for people with epilepsy. These experiences of stigma are shown through the categories of disclosure and lack of understanding about epilepsy. The following findings provide new insight into how the impact of stigma is currently experienced for these people with epilepsy within a sports and exercise setting as well as methods used to decrease stigma. Pseudonyms are used throughout these findings.

Disclosure

Participants shared differing opinions concerning disclosure; each depended on the sport or exercise setting, the social support around them, and the individual's seizure frequency and type. The following section presents the two main themes concerning disclosure: disclosure to those in authority and disclosure to other exercise/sport members.

Disclosure to those in authority. Within a sports/exercise setting, disclosure of one's epilepsy to a safety official (e.g. a lifeguard) or coach is recommended. However, as shown by some of the responses from the participants, the feelings of being 'different' outweighed the safety aspects of disclosure.

Swimming was one of the most common activities for the participants. In response to the question of 'Do you tell the lifeguard you have epilepsy?', there was a mixed reaction. Half of the participants shared that they did disclose their epilepsy if their seizures were not controlled or they were worried about the occurrence of a seizure whilst swimming. However, half of the participants said they would not disclose, as this would cause them to be seen as different and 'a marked man'. When questioned as to why that would bother them, one participant responded:

My experience with that [disclosure to a lifeguard] is that I'd be, not embarrassed, that's the wrong word. But if I tell them, I'd feel like they'd be staring at me the whole time I'm in there. **(Laura, Focus group 2)**

Others commented that since the lifeguard was trained, there would be no need to disclose their epilepsy. Also, some participants felt confident that disclosure was not needed because of their pre-seizure warning:

I've never done that [told the lifeguard]. I haven't swum for about 12 months now, but when I've done it, I never felt the need to tell the lifeguard because, they're trained. ... And I also think the type of seizures the two of us [other participant] have, you'd have enough warning to swim to the side of pool. Cause even if it's a big pool, you're not going to be more than a minute away, or less than that, say 30 seconds to the wall that you'd be able to grab. **(Adam, Focus group 2)**

Although another participant (Laura) in the same focus group shared the same opinion, the third participant (Penelope) in this focus group shared her experience of having a seizure in a pool and, although she told the lifeguard prior to swimming, he did not notice she was having a seizure and she had to be rescued by her husband who was swimming with her. The other two participants (Adam and Laura) were quite shocked at this; however, they still remained confident in their decisions not to disclose as they stated that their pre-seizure warnings (30 seconds to 1 minute) differed to Penelope, who had no pre-seizure warning. For another participant, the lack of disclosure was a result of the fear that he will be told not to swim and confidence that if a seizure did occur, his swimming partner would help him:

Um, cause I'm usually with someone who is a strong swimmer and someone that... deals and knows my epilepsy and perhaps can, I warn him beforehand if I'm going to have a fit [seizure] and not the lifeguard. Cause I'm scared, I don't want a lifeguard

that... [says], "We can't have you in the pool" or be, like say something like that. So... cause I always go with someone, I feel pretty comfortable, so I don't really tend to tell the lifeguard. I've never had one while I was swimming in the swimming pool. I feel quite comfortable [not telling the lifeguard]. **(Darren, Focus group 3)**

Seizure frequency was a common instigator that caused some participants to disclose their epilepsy to the lifeguard. If their seizure frequency had increased recently, this made them change their mind and disclose to the lifeguard:

Only recently [I've told the lifeguard], ... if it's been a rough couple of months and epilepsy's been at fault, I'll tell the lifeguard... Otherwise, it wouldn't have occurred to me. When I was on my meds, I don't think I ever did. Off the meds, I'm much more... feel the need to make people more aware. Feel that's the least I could do...I'm a big bloke to try to get out of the pool **(Matthew, Focus group 3)**.

For another, it was her feeling of responsibility to her family that caused her to disclose recently to the lifeguard:

Again, I think, if anything were to happen [while swimming], and having four kids, it would be a tragedy, just because I didn't tell the lifeguard. So, I think for that reason... If it's me by myself, probably I wouldn't [tell the lifeguard]. But I feel I'm responsible to too many people, I should tell them **(Veronica, Focus group 3)**.

Disclosure in a swimming setting provided many apprehensive responses. A similar response was also shown when disclosing epilepsy to coaches. Penelope felt stigmatized that her disclosure of epilepsy caused her running coach to prevent her from attending:

We did go running with a particular group in [location] and one time my husband couldn't go for a particular reason, and a couple of friends that usually go weren't there so I said to the guy who ran that particular group, "Next time, I'll be coming by myself, is that ok?" "No I'd rather you didn't." I mean other people knew me and

knew I had epilepsy but he said, “I’d rather you didn’t come without your friends or your husband.” (Penelope, Focus group 2)

Although she previously had no reservations to disclosure, this reaction created apprehension and added a barrier to exercising alone or in an unknown group.

Disclosure to other sports/exercise members. Participants shared that the fear or negative impact of disclosure was felt when taking part in team sports or exercising in a group. As epilepsy is unseen, participants felt that this heightened the stigma and allowed others to ‘get away’ with stigmatizing comments. An angry reaction was sparked within the group following Penelope’s experience of being told not to attend her running group without her husband:

Laura: And that’s where I think, the whole stigma is attached. You would never say that to someone with a physical disability.

Penelope, Adam: Mhmm

Adam: You just couldn’t get away with that.

Laura: But you can get away with it, cause it’s epilepsy. (Focus group 2)

This reaction “cause it’s epilepsy” captures the feeling that epilepsy is a marginalized condition and having it means you are often treated differently. For one participant, being diagnosed with epilepsy as a child caused her to feel the negative impact of stigma within school on her previously active lifestyle:

Nobody really wanted to take me [on any school teams] anymore. So that kind of finished. ... Um, they were constantly worried I was going to have a seizure cause... I kind of, I like quite challenging sports, I’m not particularly into yoga and things like that, as you can tell. Um, so, none of them wanted to take me on sports I wanted to do.

So ...So, yeah, I didn't really do anything, which was a bit of a shame. **(Rachel, Interview)**

The result of such limitations created a negative emotional impact:

Um, [it impacted me] quite negatively I think. Cause it separates you out from your year group. Um,... which isn't great at that age. So, ... you kind of go back to school already feeling like a freak and then it's like, you can't even participate in that [sport] anymore! **(Rachel, Interview)**

Some participants expressed that initially in team settings, they felt stigmatized and feared a new team environment as a result of negative comments or reactions concerning the lack of awareness of what epilepsy is. However, this reaction changed as a result of others learning more about epilepsy.

Lack of understanding

A common sentiment expressed throughout our findings was that 'people just don't understand.' This was discussed as a reason not to disclose as it could prevent the participants from exercising in certain settings. One participant felt that joining a gym was difficult because no one understands:

Um, I think, being specific to exercise, we talked about the situation about joining the club, but I think in general, exercise and epilepsy go together, but people's attitudes are, you know, "Is that going to be a problem?" ... But it's [epilepsy] never talked about, so it's like mental illness. It's the same type of impairment, which, gets the same type of reaction. I think it's also because you can't see the condition. I think, if you had your arm in a sling, that's easier to relate to because somebody could see it. So yeah, there is a lot of stigma out there. **(Maggie, Interview)**

As a hidden illness, it seems that although a common disorder, epilepsy is not discussed because it may cause fear in some individuals. Maggie continued, 'Everybody knows somebody [with epilepsy], but it's not talked about.' This aspect of a lack of understanding heightened the desire not to want to disclose in order to avoid any negative reactions:

I find it uncomfortable telling people I have epilepsy. If I get the vibe they don't understand it, I don't want to tell them anyway. I kinda feel that some people, there's still a stigma attached to epilepsy, at least that's how I feel. I feel that they see it as almost like a weakness or "I need to keep an eye on that person", so I choose who I do tell anyway, maybe for a social reason. I don't want them thinking I need special attention. **(Laura, Focus group 2)**

In addition, one participant felt that the lack of understanding about epilepsy and its hidden nature caused teammates to state that she can't take the pressure of sports:

It feels a little bit like there's still a stigma attached to it [epilepsy]. Like there's still a... for me, my frustration is, people are always saying, "Ah, you're under stress. You can't deal with the pressure and so you're having a seizure." So it's like this really overt sign of, "You can't handle the pressure." You know what I mean? But actually, I can! My body can't, but mentally I can. ...So it's like, "Oh gosh, she can't handle the pressure of this match so she's had a seizure!" ... **(Kimberly, Interview)**

Upon disclosure, one participant shared her anger at people's negative reactions to what she should or should not do as a person with epilepsy:

I started doing couch to 5K which the NHS do, so that involved a little bit of interval training. I find it absolutely fine. A few people have actually said to me, funny enough, "Should you do that with your condition?" It's almost like, you want to go...

“I want to do it more now that you’ve said that. I want to prove you wrong!” (laughs)
... I’ve done a few intervals, done a few classes which are weight bearing as well, and
again people say to me, “Should you be doing that?” And I go, “I’m just going to do it
more now, just to annoy you!” (**Laura, Focus group 2**)

The lack of understanding limited the participants’ ability to exercise as and when they
wanted. Without the ability to see the disorder, participants felt others could not relate and
this increased their fear and resultant enacted stigma.

Sharing understanding to decrease stigma

When discussing the impact of sharing to enable understanding and decrease stigma, there
were mixed reactions. Some participants described the initial negative response and fear from
others upon disclosure of their epilepsy. However, they were able to teach others a bit more
about their seizures and upon having a seizure in their presence, felt a less negative reaction
as a consequence.

Darren: But if I was going to a new side [football team], like, it’s awkward
[disclosing my epilepsy], it's an awkward thing. I actually get anxious sometimes....

Interviewer: Now when you say you get anxious, do you still tell them you have
epilepsy?

Darren: Yeah I do.

Interviewer: And how do they react?

Darren: They umm, cause they don't know much about it, they kind of are... funny
with the situation, cause they don't know much about it. So I have to break it down
and explain it to them. About epilepsy, the ins and outs, what kind of seizures I have

and what to do. And then after that, they kind of ease up. But, it's once I have a fit [seizure] around them, and they see what happens, they get more comfortable. If that makes sense? Cause they understand more about it. **(Darren, Focus group 3)**

Although disclosure aided Darren in this instance, this was not the case for everyone. As shown in the previous section, trying to create more understanding could cause fear and a barrier towards exercise. Unlike Darren, for Rachel, having a seizure during training created an increase in negative stigmatic reactions:

‘Um, most are okay [about my epilepsy]. Um... we did have some hiccups in the summer, where a couple of people didn't want to get in a boat [with me]...’. (Rachel, Interview)

For some participants, being open about their epilepsy decreased their feelings of felt stigma. However, it did not always decrease enacted stigma, as shown in others fearing a seizure or distancing themselves from participants because of this fear.

Discussion

Our research explored the experiences of people with epilepsy within a sports and exercise setting and provided new insights into how stigma may affect people with epilepsy. The work also is informed by the wider literature around stigma and hidden illness /disability (Vickers 2000) where similar key aspects are discussed concerning incorrect knowledge and moral judgements concerning hidden disorders. Prior to discussing the lack of understanding as one cause of stigma, the topic of disclosure will be presented.

Disclosure

Disclosure was a finding that was linked with both felt and enacted stigma. Previous research has shown felt stigma in relation to disclosure to lifeguards as well as to officials in

swimming competitions (Collard and Marlow, 2016a). Our results have added further incidents of such stigma and have presented the reasoning behind why disclosure can have a negative impact. The feeling of 'being different' added to the reasoning for why the participants would not disclose their epilepsy to the lifeguard. Linked with identity, some of these participants resisted disclosing their epilepsy because of the identification of being a person with epilepsy. This made them feel 'marked', something that they did not want, particularly because without disclosure, they could hide, confirming the concept of stigma as described by Link and Phelan (2001). Troster (1997) presented comparable findings in the desire for people with epilepsy not to disclose, therefore limiting potential negative social consequences. Similar statements were expressed by other people with epilepsy within a sports and/or exercise setting (Scarfe and Marlow, 2015; Collard and Marlow, 2016a). In our findings, for those who did disclose, the feelings of 'being different' were less important than their safety, as they felt safer if they disclosed their epilepsy. The reasons as to why and the various factors involved in disclosing epilepsy in a sports/exercise setting, particularly within a swimming setting, adds new insight to current research.

Within a team or gym setting, participants battled with the idea of whether they should or should not disclose their epilepsy. Participants struggled to disclose because they feared the reaction from others. These are key findings and provide first-hand insight into the struggles of disclosure. Such examples of felt stigma show that although not everyone received a negative reaction, they feared that the negative view of epilepsy would cause enacted stigma. As shown in previous research (Collard and Marlow, 2016a, 2016b), when a seizure occurs within a sport and/or exercise environment and is unexpected, this can cause negative sentiments. Kilinc and Campbell (2009) reported similar findings in relation to disclosure of epilepsy in general and this current work adds to the much wider literature of the stigma of living with a hidden illness or disability (Vickers, 2000). Additionally, this

aspect relates to the social representation of mental illness which connects with epilepsy as a hidden disorder (Jodelet, 1991). The hidden aspect of epilepsy allows people with epilepsy to conceal their disorder and choose to whom to disclose. However, as shown in this and previous research (Raty and Wilde-Larsson, 2011), people with epilepsy also realize that concealment aids the lack of understanding and further stigmatizes the condition. Future research could explore this aspect of disclosure within different sport and exercise settings.

Lack of understanding

Lack of understanding was another core theme and is prevalent in research exploring stigma (Raty and Wilde-Larsson, 2011; Schneider and Conrad, 1980). Many people show an incomplete awareness and understanding of epilepsy (Scambler and Hopkins, 1986). As shown within these findings, this adds to the fear of what epilepsy is and causes people with epilepsy not to disclose, although often they would be safer to disclose. Research shows that in the general population, individuals who knew about epilepsy were less likely to report a negative attitude concerning the person living with the condition (Jacoby et al., 2004). Also, our findings confirm that teaching others about epilepsy is one way of decreasing possible negative attitudes and occurrences of stigma (Jacoby et al., 2004). Within our findings, explaining epilepsy in detail was used as a method of lessening possible stigma. However, this did not always have a positive effect, as for one participant (Rachel), it caused a teammate to avoid her and for another (Penelope), it prevented her from taking part.

These findings show that there is a common thread of stigma for all the participants as a barrier to exercise. When asked, each had a story to share about their experiences of stigma within a sport and exercise setting. In general, this was the result of a lack of understanding of epilepsy. However, participants' non-disclosure also aided such lack of understanding. One way to resolve such issues would be to encourage more people with epilepsy to be open

about their epilepsy. However, this is not easy. As a person with epilepsy, it is only through conducting research such as this that I (SC) have developed the confidence to become more open (Scarfe and Marlow, 2015). In my personal experience, I have seen that often people do not understand. However, once I disclosed my epilepsy, their fear and concern reduce. This may not occur for all, but as discussed by some of the participants, it may be a stepping stone to reducing stigma and increasing understanding. Research provides examples of similar experiences of decreasing stigma if the individual with epilepsy is open and confident about being a person with epilepsy (Kilinc and Campbell, 2009). Research exploring the topic of exercise professionals' knowledge of exercising with a hidden condition (e.g. diabetes) shows that further education of the condition in relation to exercise is needed, thus showing similarities within the need for increasing understanding within this setting (Matthews et al. 2017). Future research should address this further and specifically explore the understanding of epilepsy by health professionals within a sports and exercise setting, for e.g. personal trainers, coaches, and lifeguards. Also, it would be interesting to explore the most comfortable and successful ways of sharing understanding for all concerned. Such research would be important in decreasing stigma for people with epilepsy.

Conclusion

As shown by these findings, stigma does occur for people with epilepsy within a sport and exercise setting and, as a result, can create unsafe circumstances. Although most safety recommendations discuss disclosure in a sporting setting (Epilepsy Action UK, 2014), many participants felt that this created a feeling of being different and an outsider, something that they did not want to be. To achieve a balance of safety and comfort in oneself as a person with epilepsy, future research should explore ways to increase acceptance of being a person with epilepsy in a sport and exercise setting.

Notes

i. Tonic-clonic seizure: Physical manifestations typically are seen as stiffening of the body, clenching of the jaw, stopped breathing, and jerking of the limbs (Barrett and Sachs 2006).

Partial seizure: Complex partial seizure typically manifests in a loss of awareness, facial movements, such as grimacing or lip smacking, and hand movements. Simple partial- the person remains alert, may feel strange, and is able to interact. These seizures are brief, lasting seconds to less than 2 minutes. (Epilepsy Foundation, 2017; retrieved from: <http://www.epilepsy.com/learn/types-seizures/focal-onset-aware-seizures-aka-simple-partial-seizures>)

Absence seizure: Lapse in awareness, sometimes with staring, and can begin and end abruptly, lasting only a few seconds (Epilepsy Foundation, 2016; retrieved from: <http://www.epilepsy.com/learn/types-seizures/absence-seizures>).

Myoclonic seizure: Physically manifest in brief shock-like jerks of a muscle or group of muscles. The individual is usually awake and able to think clearly (Epilepsy Foundation, 2016; retrieved from: <http://www.epilepsy.com/learn/types-seizures/myoclonic-seizures>).

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