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## Abstract

Through a phenomenological approach, this article explores the identity conflict that arose within a female runner after diagnosis with epilepsy. Utilising a three month autoethnography to track her experiences of returning to running, the first author narrates the effect of epilepsy on her identity formation. Providing a voice that is absent from a research area dominated by statistics, the reader is asked to involve him/herself in the world of this athlete and in turn embrace the use of narratives as a valuable coping mechanism for those with chronic disorders.

Keywords: autoethnography; epilepsy; exercise; identity; qualitative

*Flashback November 2001: 'Epilepsy? WHO has it? (pause) What is it?' There I sat in the neurologist's office, these words echoing inside my head. I was being diagnosed with complex partial seizures. I had epilepsy. A rebuttal is thought, but not spoken: 'I am an athlete, I can't have epilepsy'. The shock that someone like me could have epilepsy didn't seem real. 'I am healthy. I am an athlete!'*

## My running life

Running has been a passion of mine since I went on my first 'real' run, aged 13. I still remember now the feeling of strength and confidence as I ran. It was as if I had found the sport I was meant to do. Upon my father's urgings to follow in his footsteps, I joined the school track team. My love for the sport grew quickly and was spurred on by the rapid ability to win every race, beat all the boys on the team, as well as the pleasure felt through physically and mentally pushing myself in every workout and race. As a runner, I felt strong; I felt confident. Although in my everyday life I was shy and quiet, when it came to running, I was on show and loved it! Devoting all my extra time to running, my life revolved around the sport. Running defined me; I was a runner. Known as 'the runner' at school, I thrived on the attention, attention that would not been there without this dedication to the sport. This

outside praise strengthened my running identity and was a constant confirmation that this was ‘who I am’.

*Flashback: Floating down the track, I can feel the strength in my legs and mind as I move. Every step solidifies that this is what my body was made to do. Every step solidifies my passion. Running, what does it mean to me? Peace, relaxation, control, power, confidence...*

As my personal identity solidified around my athletic identity and I worked my way up the sporting ladder, I was pushed back when diagnosed with epilepsy during my freshman year at college, aged 19.<sup>1</sup> I went to a Division One University to run, to eventually become an Olympian, but in a sudden statement by a neurologist that, ‘You have epilepsy’, I realised this dream may not come true. Initially, I did not know the extent to how this would affect my running. However, over time, it became apparent that my initial fears that this diagnosis was life-changing were becoming true. With seizures often occurring on runs, the roads were too dangerous a training ground. Instead, I was confined to running endless laps of the track, or indeed, stayed at home as a new fear of running developed. Although an unseen disorder (Jacoby and Baker 2008), epilepsy made me feel physically incapable. Having this physical limitation for a person who is accustomed to a healthy and fit body is usually shown within literature for someone who has had an injury (Sparkes 1996). However, I still looked healthy on the outside. Physically, I was not warped, limping, or have lost physical health (Sparkes 1996). Instead, my physical appearance was that of a healthy, young, female runner. My outside shell (Sparkes 1996) was a mask that I wore, and increased my frustration in the inability to maintain my

identity. This paradox seemed to create a negative impact on my mental state and encouraged me to try to keep running, denying any physical limitations, and thus preserving my athletic identity (Sparkes 1996, Allen-Collinson 2005). As a result, I was constantly fighting my own self-identity. At the end of my four years at University, I decided I could no longer run with epilepsy as the consequential fear and anxiety of hurting myself on a run was overwhelming.

Although it has been 10 years since my diagnosis, my love for the sport has not changed over the years. I crave a run, but withhold. I see runners on the streets and wish I could have that ‘floaty’ and energetic feeling again; the feeling that only a run can bring you. I do not know why at this point in my life I decided that it was wise to try again, but I felt the desire to be a runner once more.

### **Epilepsy and exercise**

Research has shown physical exercise to be beneficial for most people with epilepsy (PWE) because of the positive effects on seizure control and well-being (Nakken et al. 1990, Wong and Wirrell 2006). Although epilepsy is one of the most common neurological disorders (Arida et al. 2009),<sup>2</sup> the lack of first-person experiences raised the question as to whether the positive effects of exercise (Sirven 2009, Arida et al. 2013) hold true to the experiences of PWE. Upon researching the topic, I felt unease at the missing elements within research as experiences such as my own had not been documented. Where were the lived experiences of PWE, showing the fleshiness and sensuousness of what it is to exercise with epilepsy? Where were the stories presenting the constant psychological struggles of exercising with epilepsy? Am I the only one who has to mentally prepare prior to each run for fear of the dangers of having a seizure during exercise? Am I the only one who can no longer train

for a competition as I am not able to train consistently enough due to constant seizures?

The lack of the lived experiences of PWE caused me to feel I had no voice within the medical and sport communities; I felt alone, with no appropriate models or guidance. Fuelled by these questions and frustrations, I decided to embark on a journey of returning to running. Documenting this journey (see research process section below), the aim was to test my own self-boundaries, face my fears, and present the psychosocial impact of being a runner with epilepsy.

### **Filling the gap**

To date, the absence of qualitative research investigating epilepsy among athletic populations is noticeable within the health, sport, and psychology literature. As a result, an understanding of epilepsy in sporting/exercising populations is still in a nascent state, with the scant literature available coming from the medical field and being quantitative in nature (Nakken 1999, Eriksen et al. 2002, Sirven 2009, Arida et al. 2013). There is a need for the voices of athletes with epilepsy to be heard and understood, to gain valuable insight into the struggles and sporting barriers faced by these athletes. These stories are not only pertinent to PWE, but also those in the medical and sport communities who may not be aware of the psychosocial struggles that PWE may face if exercise is affected by seizures. Consequently, this new insight could lead to an appreciation of a different story, greater empathy, and an understanding that might lead to the development of coping mechanisms and possible exercise intervention/adherence advice for PWE. Therefore, this paper seeks to initiate the understanding, the feeling, and the experience of an athlete with epilepsy, through qualitative means.

In a constant search to find someone else like me, an athlete with epilepsy who

could describe a similar identity crisis, I was left wanting. Undertaking this autoethnography, I desire to present life as a person with epilepsy who embarks on a daily battle with her body. Resonating with my identity was Corbin's (2003) concept of an illness identity, where one's perception of a healthy body and lack of control of one's body can alter his/her identity. This loss of self is further shown by Charmaz (1983, p. 168) as she stated, 'chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued ones'. With such losses causing disruption in identity, what occurs when the illness is not always physically present? What occurs to that person's sense of self when he/she appears healthy, physically fit and capable of doing physical exercise as before, but then retreats to becoming visibly ill? These are the questions I face daily.

Exploring the concept of a hidden disorder's affect upon identity has been shown within literature (Dickson et al. 2008). However, the majority of this research examines the relationship of the labelling of disabled or one's quality of life with an invisible disorder/illness (Rhodes et al. 2008). In relation to exercise and identity, there has yet to be research exploring the topic for an individual with epilepsy. Through this autoethnography, I aim to address this gap.

Examining current literature, there is an emergence of research using narrative techniques to present the first person perspective (Sparkes 1996, Ellis 1998, Allen-Collinson 2005, Jegatheesan 2005). Although varying in different styles, the common interest of communicating an experience drew me in to presenting my running experience in such a way. Through the use of narratives, a first-hand account of exercising with epilepsy will be presented, filling the gap that is apparent within the numerous quantitative and medical case studies on the topic (Nakken

1999, Eriksen et al. 2002, Arida et al. 2009).

## **Research process**

As a result of my strengthening desire to regain my 'runner identity', I devised a three month training plan leading up to the completion of a 5 Kilometre (5 K) race. Aiming to recapture the essence of my training past, I felt that entering a competition would provide an appropriate challenge and, as a result, present my story of a female runner with epilepsy. As competition was so important to my previous 'runner' identity formation, it seemed key to include this element in this journey to enable the gain of this past identity. Three months was chosen as this would provide a good training base for returning to competition (Benson and Ray 1998). As a middle-distance runner previously, the 5 K distance was deemed appropriate as I commonly ran 5 K races during the cross country season and was, therefore, a familiar 'race' goal. Daily diaries were used throughout the three months to document this research experience. As I normally keep a seizure diary to record my seizure activity as well as any 'strange' seizure symptoms, the additional daily diary entries were not difficult to add into my routine. Pre and post-run diary entries allowed the capture of momentary thoughts and emotions regarding my physical and mental state prior to, during, and after a run, resulting in daily tracking of emotional states and seizure activity. Diary entries were transcribed weekly and after each month, thematically analysed using interpretative phenomenology analysis (IPA) (Willig 2001). IPA was chosen for its ability to focus on the experience of the individual's world and as researcher, provide an interpretation of this experience (Langdrige 2007). The step-by-step analysis allowed themes of emotional response, identity, social support, body, etc. to emerge; themes that emerged meaningful as I went through this

research process. After analysing the diaries over the course of the three months, two main themes became apparent. One, the emotional rollercoaster that was exercising with epilepsy (to be discussed in a subsequent paper); and two, the identity conflict between my epilepsy and athletic identity. The theme of identity was chosen as the main phenomenon under investigation within this paper, as it was a recurrent and influential theme throughout the three months (Dickson et al. 2008). To allow a focused look at identity, this paper will present the two narratives that best bear witness to my identity conflict.

As stated in Tenni et al. (2003), discussions with others are needed when dealing with one's autobiographical data. Thus, I discussed my analysis with my co-author, who acted as a critical friend (Carless and Sparkes 2008) to challenge my analysis and provide a listening ear throughout the study. I found the presence of an 'outsider' to be beneficial. Throughout the research process, particularly during analysis, my co-author made me keep sections that I was too embarrassed and felt too emotional to share. For example, I would edit far too much of my diaries after analysis as I was afraid it made me look weak or even stupid. I found that upon analysing my diaries, I would often become quite upset. The reading and re-reading of my thoughts was too much to handle at times. Although I found this as a negative at the time, my co-author encouraged me to face these thoughts and use the resultant emotions as a way to spur on more writing. Therefore, not only did having a co-author make this autoethnography more 'real', but she also helped in aiding me to face my fears, which are discussed further on within the narratives.

Throughout this autoethnography, flashbacks are presented to add depth to my story. Whilst writing the background aspects of this autoethnography, as well as during daily diary reflections, flashbacks flooded over me. Therefore, it seemed fitting

to add them to the finalised text to provide a more vibrant view of my running experience.

Utilised in her autoethnography, Jegatheesan (2005, p. 668) provided flashbacks to intertwine her ‘multiple levels of mind states’, as well as to provide ‘a world that I was an inhabitant of’ (p. 669). Aiming to present my world as a runner with epilepsy, these flashbacks are written in italics and are the memories of my running life before and post epilepsy diagnosis, aiming to allow others to bear witness to my passion for running, as well as the effect epilepsy had upon my normal running routine.

The following narratives are presented as one piece of writing, however, it is ‘messy’ (Smith and Sparkes 2009), marked by split segments of my diaries.

Although thematically analysed, each narrative is presented as one constant stream over time. As a result of reading these narratives, I am urging the reader to emerge him/herself into my world, that of a person with epilepsy. Allow yourself to see the daily struggles, yet think about how one may overcome them. I do not desire these narratives to be judged on flow of information, but on how they make you, the reader, understand and empathise with the experience of a runner with epilepsy and the identity issues involved. I am upholding Denison and Rinehart’s (2000 p. 3) beliefs in how narrative work should be written, hoping it will also ‘contribute to an understanding of social life while also being artistically shaped and satisfying’.

In the style of a research story (Markula and Denison 2005), these two narratives portray my identity resolution over time. Within each narrative, events are in chronological order: (1) epilepsy bracelet: depicts the difficulties in identifying myself as a person with epilepsy and the resultant impact on my running life; (2) the runner: focuses on the struggle to fight my previous concept of what it means to be a runner and thus the acceptance of my physical limitations.



### *Epilepsy bracelet*

‘Where am I?’ My eyes are open, but I can’t see. Slowly shapes start to take form.

‘Where am I?’ Intense fear overwhelms me. Head pounding. ‘Where am I? What just happened?’ Then I realise, ‘Seizure. Damn! It must have been a seizure’. Head pounding.

I check my body, making sure I haven’t hurt myself during the time I was out,

‘Good, I’m fine. Where am I?’ It looks like I’m in the woods. ‘Why am I in the woods?’ I start walking, praying I am going the right way. ‘What was I doing? What was I doing?! Oh yes, I was running!’ I slowly start to run. Nothing looks familiar in these woods. Endless trees, dirt, darkness, no one in sight. The sense of fear is overwhelming.

‘Is it a good thing or a bad thing that no one is around? How will I get home? Where do I go?’ Head is continually pounding. ‘Keep running and maybe you will remember’. Suddenly, a familiar sign, ‘The log! I remember that log! Oh man, I’ve been going the wrong way!’ As I turn around, I have a flash of my mom saying, ‘You should be wearing your epilepsy medical bracelet’. The feeling of guilt overwhelms me, she was right, I should have been wearing it. Then, if someone found me at least they would know something was physically wrong with me, and I wasn’t crazy! ‘Why does this happen to me? Why do I have to have seizures? How long have I been running for? I must still be lost!’ Head pounding, the exhaustion of the seizure is overwhelming. I try to keep my frustration down to keep my body moving.

Suddenly, I see the light through the trees. ‘Finally’. It must be the end of the trail. I am almost there. Exhausted, head pounding, I focus on the light.

That had to be the scariest moment I’ve had running while having a seizure ... I decided to wear my bracelet after that.

During my run, I seemed to be lost in the middle of endless houses and had a repeat

flash of mom saying, 'You should be wearing your epilepsy medical bracelet'. I still wasn't wearing it, although after my previous seizure during running, I had promised myself and my mom that I would. Again, I felt guilty and scared. Guilty for the fact that I was disobeying my mother and scared of what may await me when I come out of each seizure. I could be hurt, with strangers; I don't even want to think about any other possibilities. However, I hate wearing that bracelet. I look at it and it reminds me that I'm different, that I have limits; it causes epilepsy to become real and visible...

Why do I feel more comfortable in my runner identity than being epileptic? There is a reason. Fear of being epileptic I think. It scares people ... , you can see it in their faces once you tell them. It is an unknown disorder where people like me look normal, but can suddenly change into something different, something scary and unknown.

Epileptic ... This word makes me cringe. Defining myself as having epilepsy makes me want to distance myself even more from this disorder. I am not epileptic. I don't know what I am, but I am not epileptic.

Sitting here on the edge of my bed, my heart beating in anticipation for what is to come. I try to assure myself, 'I will be fine'. I feel ready to go on my run. 'Wait, my bracelet'. I secure my bracelet, not on my wrist, but on my shoe laces, I can't quite have it on my wrist yet, too much of a reminder. Memories suddenly flood in. Fear. The loss of my running life. Fear. As I secure my bracelet on my laces, a sudden sense of security overwhelms me.

I love running, but it is scary ... It is a combination of the actual loss of control of my body while pushing myself to the unknown, with the fear of what the consequence of having a seizure means in my life: upping my dosage, more side effects, less running. I'm living with so many side effects from my drugs, I don't feel like the same person anymore ... I just sometimes want to ignore a seizure and pretend

it didn't happen, so I won't have to change doses, especially if they are tolerable. At least then I could keep running and not feel like epilepsy has taken over my life ... I'm scared of my first track workout because at any time I could have a seizure and if I do, then that means I indeed have exercise-induced seizures. I will have to face it and accept it once and for all ... I am scared to go ... I'll wear my bracelet.

Prior to epilepsy I was mentally tough; I could run through anything. Injuries, sickness, nothing could deter me from running or competing. *I ran for 6 weeks on a broken ankle. Thinking I had only badly sprained it and desiring to finish out the season, I kept running, although painful. It was so severely sprained, that after the 6 weeks, I had to have it in a boot for 3 months as I ended up fracturing it in two places!* After epilepsy, I've become a mentally weaker version of myself ... I need to run today, but my head hurts and I'm a bit tired. Don't want to risk a seizure, will just stay at home ... Haven't run in 4 weeks now, scared to go as I may have a seizure as I'm so out of shape. Although I used to be able to push my body to the extremes of pain and fatigue, now, I no longer let myself even contemplate running through those elements. I want to revert back to the old me. I want to be tough again. Smart, but tough ... But, I've always read that my seizure type is the hardest to control, so what's the use ... Guess I better wear my bracelet.

### ***The runner***

I loved getting dressed in my running gear again. I looked in the mirror and looked like a real runner again. I still have a runner's body, it makes me excited ... Running, watching the trees race by, the sound of my feet touching the pavement, my heart pounding, and heavy breathing. It feels so good to be out here again. I have missed this feeling.

My run was at a comfortable pace, hopefully it was fast. I would hate to think

that I've turned into a slow runner. The anticipation of being able to say, 'I am a runner', instead of lying that I am a runner makes me so excited. It's as if I'm back where I belong ... In my runs, I am starting to feel 'floaty' again ... I feel more confident in my running and myself as a runner. I feel I really am a runner again... Here I am, papers splayed across my desk. I take my pen, get out my diary, and slowly fill out day by day, week by week, my training schedule. Planning my daily runs, weight training sessions, interval workouts, hills workouts, I am so happy to be able to do this once more. I have missed the planning! I am getting so excited of my future in running again.

I was talking to my sister and she was freaked out at my training schedule. She thinks I am going to be pushing myself too much. She says I still have a competitive mindset and need to think like a recreational athlete when I plan. I guess she's right. Until I know I can handle intense exercise, I should just take it slow, not to dive so deep into the water that I drown, but it's so hard. I want to do the speed sessions, the mileage, the whole package! I don't want to just jog a 5 K. I could do that right now. That's not racing...

Just had another seizure on my run. Now it's been a couple days before I have had the courage to run again. This battle is ongoing. Why can't I just be a normal runner?

It seems I'm being a bit too overprotective as I keep changing runs to days off for fear of seizures. I don't know if this is the safe way to run or the scared way to run. It's frustrating. I think my old competitive mind realises that this is too easy, but maybe it is how I have to run now. I don't know ... Prior to diagnosis, I used to force myself to run no matter what because I had no other life. Now, running must be a side path of my life. Something I love and want to take part in again...

All by myself, I feel like I can't run very slow and just can't do a real easy going through the paces run. That's one of my problems, I have a competitive mind and I always want to achieve more. When I feel myself flagging, I have to push harder. I can't just go slow. I feel like a wimp if I do...

I went to my sister's race today to support her and it hurts watching the runners. I am training so that I can one day try to race, but will I truly be able to race like I want to? Race to my limits, push through the pain, feel like I've given 110%? Or, will I always have to run controlled and feel satisfied with the fact that a good effort without seizures is a job well done? That second option doesn't feel like how a runner should be. I still can't accept a new way of running, or at least find it hard to accept I may not be able to compete once more. It doesn't seem real to me. I love competing, pushing myself. Without that, I feel like I am not me. It's another part of myself that epilepsy has taken from me...

### **Reflections on the research process**

Aiming to not be another person with epilepsy who fears exercise, I challenged myself to run again. However, facing setbacks, I was unable to achieve competitive fitness in three months and as a result, did not race. During the three months, I had to come face-to-face with a concept I had been in denial of for eight years, my own physical limitations. By maintaining the 'competitive runner' as my athletic identity (Weiss 2001), I limited myself from running in any other way. Thus continued to keep the mind-set that to run means to compete, to run means to be fast, and to be a runner, I cannot just run. Throughout the three months, my refusal to adapt to a new level of 'recreational athlete' appeared to be the main deterrent preventing me from participating in the sport I love. Although it is still an ongoing challenge, this

research process has allowed me to begin to come to terms with my present body and thus realise the need to accept the loss of my athletic identity as I once knew it. This acceptance is still fragile; still an ongoing battle. I still have weeks where I have had no seizure for seven days, have run for 3 days and feel that I am on way to being an athlete once more! This dream is then smashed when I have multiple seizures and then go a week, two weeks without running again. I do not know how or if this will ever change.

The frustration in this ongoing desire to recapture my former athletic identity was enhanced by my body's healthy appearance. Finding it difficult to separate my physical appearance from my embodied state, I was left emotionally deflated as I faced my bodily limitations again and again once a seizure occurred. Differing to research where the participants had to defend to others why their weaker bodies, although with a healthy appearance, were not physically fit (Dickson et al. 2008), I had to be told to withhold running beyond my physical limits. The ongoing conflict of visible vs. invisible aspects of epilepsy and its affect upon my athletic identity prolonged my biographical disruption (Goffman 1963, Charmaz 1983). I clung on to the past memories of my healthy body, and thus maintained a disrupted identity whilst in the present, coinciding with what has already been seen in others with chronic hidden disorders (Goffman 1963, Charmaz 1983, Dickson et al. 2008). However, in comparison to other chronic disorders, epilepsy has the change of visibility once a seizure occurs. Other disorders may have physical symptoms that arise (Dickson et al. 2008), but it appears that there is a distinct difference for an individual with epilepsy. This constant change in visibility created an ongoing cycle of hope, frustration, and sense of loss which seemed unending and added to my identity confliction. As there is a lack of research investigating the visibility/invisibility

of epilepsy in the athlete with epilepsy, further research can delve within this concept and help PWE cope with the acceptance of the disorder.

During the three months, I found the use of writing my daily diaries, or telling my story, to be therapeutic, reflective and as a result, a coping mechanism. Similar results have been shown within other research investigating illness/disorders (Sparkes 1996, McMahon and Penney 2011). More research needs to be performed to see if journal writing and opportunities to talk openly about one's illness can be a useful coping mechanism for individuals with epilepsy.

### **Concluding thoughts**

By recording and divulging my innermost thoughts through these past three months, I have found the cleansing benefit of the telling of a narrative upon a hurting body and mind. In regards to viewing myself as an individual with epilepsy, over time, I have begun to embrace that epilepsy makes up a large portion of who I am. I view myself as an athlete as I cling on to my competitive spirit and athletic talents. However, I also view myself as an individual with epilepsy. This dual identity has created intense frustration as one part of me hinders the other. The invisibility of my epilepsy prior to a seizure increases this frustration. However, this research process has allowed me to voice this frustration, thus allowing the impact of my epilepsy on my sporting life to be less intense. I now believe the two can co-exist within me. This being said, I continue to have the daily battle of 'to exercise or not to exercise', however, this process has allowed me to become more accepting that the 'no exercise days' do not mean the end of my exercise life and subsequent athletic identity.

As shown through the ongoing pursuit of identity confirmation, this research

draws attention to the impact of my epilepsy and athletic identity upon my exercise life. Therefore, it is desired that the awareness of such an identity conflict for PWE will allow the medical and sport community to develop ways of coping with this duality of PWE. Furthering this research, it is hoped that exploration within the topic of identity and athletes with epilepsy will enable successful maintenance of a healthy psychological and physical lifestyle for PWE after diagnosis.

Upon reading this story, it is hoped the readers will recognise the importance of narratives amongst athletes and exercisers with epilepsy as well as the reflective benefits to the individual, and in turn, will consider the usage of such practices to enhance awareness of the experiences of an 'athlete with epilepsy'.

## Notes

1. I was diagnosed with complex partial seizures. These typically manifest in a loss of awareness, facial movements, such as grimacing or lip smacking, and hand movements (Richard and Reiter 1995).

2. It is defined as 'a chronic condition in which a person has recurrent seizures' (Dubow and Kelly 2003 p. 501), which are the occurrence of neurons within the brain discharging excessively and at the same time (Richard and Reiter 1995, p. 24). There are two main classifications of seizures: generalised or partial (Barrett and Sachs 2006). Generalised seizures occur when most of the neurons within the brain fire simultaneously, resulting in, for example, a tonic-clonic seizure. Physical manifestations are typically seen as stiffening of the body, clenching of the jaw, stopped breathing, and jerking of the limbs (Richard and Reiter 1995, Barrett and Sachs 2006). A partial seizure is a result of excessive neuron activity localised in a particular area of the brain, e.g. the temporal lobe, frontal lobe, etc. (Richard and Reiter 1995).

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