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"It's such a vicious cycle": Narrative accounts of the sportsperson with epilepsy

Sarah S. Collard*, Caroline Marlow [1]

University of Roehampton, Whitelands College, Holybourne Avenue, London, SW15 4JD, England, UK

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A B S T R A C T

Objectives: There is an abundance of quantitative and medical research promoting the benefits of exercise for people with epilepsy. However, the psychosocial barriers and benefits of exercising for the sportsperson/people with epilepsy (SWE) are absent. This research aims to present the narratives of SWE over time and as a result, develop further understanding of the psychosocial impact of exercising with epilepsy.
Method: A holistic-content and structural narrative analysis were used to explore the exercise experiences of three SWE over the course of one year. A creative non-fictional technique was used to present first person narratives, therefore providing the SWE's voice for the reader.
Results: Narratives of 'vicious cycle' and 'roller coaster' presented complex and multi-thematic storied forms, with time and the hidden nature of epilepsy having a strong impact on narrative formation. Vicious cycle presented the cycle of desiring to exercise, but prevented from exercising because of uncontrolled seizures. This resulted in frustration and feelings of a lack of control, which subsequently increased the desire to exercise and created a cycle with no clear end. Roller coaster presented the constant psychosocial and physical undulations that epilepsy can create for a SWE over time.
Conclusion: These narratives reveal that exercising with epilepsy has a constant and on-going positive and negative impact on the life of SWE. However, these narratives also show that it may be through the process of acceptance of their body's limitations that a healthier mental and physical state may result for the SWE.

1. Introduction

Epilepsy is "a chronic condition in which a person has recurrent seizures due to an underlying cerebral process" (Dubow & Kelly, 2003, p.24). As one of the most common neurological disorders, epilepsy affects 50 per 100,000 people in the UK per year and 50 million people worldwide (Aydemir, Vu Trung, Snape, Baker, & Jacoby, 2009). Research has shown physical activity to be beneficial for most people with epilepsy (PWE) because of its positive effects on seizure control and personal well-being (Pimental, Tojal, & Morgado, 2015). However, PWE experience many barriers to exercising with epilepsy. First, as the medical community have not reached a consensus about the benefits and promotion of exercise, many PWE are inadequately informed about the possibilities of exercising (Sirven, 2009). Second, PWE have reported a fear of seizures and seizure-related injuries (Arida, Cavalheiro, da Silva, & Scorza, 2008). Third, looking at the effect social support has upon a PWE's decision to exercise, Ablah et al. (2009) found that 68% of 412 surveyed epilepsy patients were actively discouraged by family members or another influence. As a consequence of this on-going hindrance, and despite the specific physical and mental benefits of physical activity, exercise is still not a regular occurrence for PWE (Dubow & Kelly, 2003). The resultant inactivity levels have shown to contribute to social isolation, low self-esteem, weight gain, and depression for people with epilepsy (Pimental et al., 2015).

Narratives of everyday life for PWE have focused on the impact of epilepsy on quality of life, mental state, social support, and the side-effects of medication (Schachter, 2008). However, exercise has been noticeably absent. As a result of this limited source of qualitative research, I (Sarah, first author), a sportsperson with epilepsy

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* Corresponding author. Present address: Bournemouth University, Faculty of Health and Social Sciences, Royal London House, Christchurch Rd., Bournemouth, BH1 3LT, UK.

E-mail addresses: scollard@bournemouth.ac.uk (S.S. Collard), caroline@landmconsulting.co.uk (C. Marlow).

[1] Present address: L & M Consulting. www.landmconsulting.co.uk.

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(SWE), published a three month autoethnography on running with epilepsy (Scarfe & Marlow, 2015). This research provided first-person insight into the constant frustrations in the inability to have a consistent exercise routine and the fear of injury during exercise, which led to the loss of an athletic identity. Although this extended current knowledge of a SWE, it did not allow for multiple voices to be heard, nor show results over an extended time period. Therefore, through the use of narrative inquiry, we will explore the lives of three SWE (people with epilepsy who desire to exercise at least 3 times a week or would like to had they not been prevented by their epilepsy) over one year.

1.1. *Narrative inquiry*

Drawing from the recent development to expand methodology from positivistic or realist forms (Smith & Sparkes, 2009a), narrative inquiry has provided an alternative methodological approach within current research. Describing narrative as a key process by which we construct, make sense, and relay our experiences, Smith and Sparkes (2009b) focused on how narratives allow people to communicate an experience. Concluding that every story is social as well as individual, Smith and Sparkes (2009a; 2009b) encourage the use of narratives as resources to encompass multiple viewpoints and circumstances of sportspeople. Furthering the idea of narratives as ‘messy,’ i.e. not fluid or constructed in regards to aesthetic presentation, they go on to discuss that human beings are messy, and therefore their narratives will reflect this.

Emphasising biographical time, the timeline over the course of one's life, as important within life story research, Sparkes and Smith (2003) focused on the effect time has on structuring a narrative. Throughout their research with men living with spinal cord injuries (SCI) within sport, biographical time was shown to affect the illness narrative, particularly as there was a change between a before and after injury identity. Viewing time as significant to narrative structure (Crossley, 2002), it is of importance to consider the effect of time within each SWE's experience. Differing to a SCI, it is epilepsy's hidden and unpredictable nature that can cause disruption for a SWE over time (Scarfe & Marlow, 2015).

Applying the approaches of Frank (1995) and Lieblich, Tuval-Mashiach, and Zilber (1998), we explored the exercise narratives of SWE. Exploring the narratives of cancer patients, Frank (1995) described three types of narratives; chaos, quest, and restitution. Within chaos narratives, an individual cannot see a way out of his/her misery, nor a hope for the future. Within the restitution narrative, one follows the plot of, “yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again” (p.77). The final narrative, quest, is described as a “hero's journey” (p.116), depicting the illness experience as an awakening, a purpose, a journey that starts with an illness and allows one to come to a new sense of self-reflection. Although Frank (1995) explored cancer patients' narratives, there are elements of similarity between a chronic illness, such as cancer, and epilepsy. For example, in epilepsy, there is the hope for controlled seizures and increased quality of life (Scarfe & Marlow, 2015; Schachter, 2008). The role of hope can be shown to provide an element of restitution, chaos, and quest, and as a result, would make it an applicable reference in examining the narratives of SWE.

Although not specifically within illness, Lieblich et al. (1998) presented narrative structures (e.g., progressive, steady and decline) as a result of investigations over time, drawing attention to the factors involved with shifts in one's narrative and the patterns that develop in an individual's life story. For example, does their story steadily advance (progressive), stay the same (steady), or is there an overall decline in the individual's story (decline). These can be seen as basic movements within a narrative, yet there could be elements to cause shifts in the progression, in other words, various life experiences that could cause a change within the structure, resulting in wavy structures, e.g., trial and error (Lieblich et al., 1998). Using these narrative structures as aims of reference, we will present the holistic narratives of SWE, individuals who have elements of visibility and invisibility with their disorder, as well as daily disruptions due to uncontrolled seizures (Scarfe & Marlow, 2015). Prior to discussing the methods used, narrative literature within health and exercise will be presented to highlight further potential parallels to others exercising with health concerns.

1.2. *Narratives within health and exercise*

Insights into the experiences of exercising with a chronic condition/illness have been shown to be an impactful way to present an individual's social construct (Moola, Fusco, & Kirsh, 2011; Smith, 2013). Smith (2013) presented ethnographic creative nonfiction narratives of individuals with SCI as a result of sport, highlighting the meaning of sport for the individual with SCI. These narratives provided empirical knowledge in a detailed and insightful manner, presenting the thoughts, feelings, and views of a newly impaired body. Presenting the variances between a chaotic view of their new body and its limitations on their previous lifestyle, to the view that this should not be the end to their sport lives, these narratives showed the impact of social interaction as a tool towards acceptance. Through presenting the narratives as social interaction, Smith (2013) advanced theoretical knowledge through emphasising the social aspects of narratives. Using narrative analysis to provide the social and cultural world of SWE, we are interested in portraying how epilepsy shapes the SWE's world. Differing to SCI, as epilepsy is a hidden disorder, these narratives will provide insight into the social narrative of *how* it is to exercise with epilepsy and the impact sport importance and his/her social world has upon the SWE's narrative.

Exploring narratives with older people and their sport uptake, Hudson, Day, and Oliver (2015) presented narratives of positive personal change, as well as decelerated decline. Researching older individuals who were enrolled onto an exercise programme, one element that structured the progression of the individual's narrative was a sense of control. For example, within the narrative of positive personal change, individuals were shown to embrace a hope for the future and accept control over their health. Conversely, for individuals presenting the decelerated decline narrative, as they are not able to stop the aging process, an aspect of helplessness or lack of control concerning aging prevailed, thus limiting the long-term positive effects of the programme. As PWE have reported the feeling they have little control over how their epilepsy affects their life (Scambler, 1989), we are interested to understand how SWE view their locus of control and how this shapes their narrative.

A stigmatized disorder, the social and cultural representations of epilepsy (e.g. tonic-clonic seizures, i.e. convulsive seizures, are the main manifestation, epilepsy is a mental illness, and one fears a person with epilepsy), can negatively impact a PWE's sense of self-perception (Scambler, 1989). Therefore, it is of interest to explore whether these representations also play a part in the formation of a SWE's narrative. Previous literature on youth with congenital heart disease (CHD) showed that exercise participation was impacted by their social and cultural world (Moola et al., 2011). Presenting narratives of realist and resistance, Moola et al. (2011) showed that within physical activity, some youth with CHD felt that physical activity emphasized the social and cultural representation of CHD as fragile, and struggled with barriers within physical activity (realist). However, other youth presented resistant narratives, challenging the social and cultural representation of being labelled as frail and not capable of what others could do. Although epilepsy narratives have shown aspects of this in everyday life (Schachter,