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(Re)creating a healthy self in and through disability sport: autoethnographic chaos and quest stories from a sportswoman with cerebral palsy

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ABSTRACT

Those with physical disabilities are at increased risk of poor physical, mental and social health. Despite widely reported physiological and psychosocial benefits of sport for disabled people's health and wellbeing, participation remains low and is in decline. Subsequently, we answer calls for greater focus on individuals' voices to understand the complexities of disabled people's participation in sport. Through a narrative autoethnographic approach we critically show and examine the lived experiences of a young female sportswoman with a disability (Gemma), as she reflects on the role of sport in, through and beyond her childhood. Framed within Arthur Frank's narratives of injury and illness, we highlight the sport-based posthumanist narrative(s) that enabled Gemma's (re)construction of a healthy self. Ultimately, we offer narrative inquiry, including autoethnographic methods, as a framework for understanding the lived experiences of children and young people with physical disabilities and practical recommendations for expanding narrative resources.

ARTICLE HISTORY

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KEYWORDS

Narrative inquiry; autoethnography; congenital physical disability; disability sport; self-identity; children and young people

Points of interest

- Despite the barriers to and benefits of sport and exercise for children and young with a disability, the number who participate remains low and is in decline.
- This research examines stories from a young woman with cerebral palsy as she reflects on the role of sport in and beyond her childhood.
- She views her participation in sport as a turning point in her life when she was struggling to work out who she was and what she could be in the world.
- Sport has enabled her to make sense of who she was, who she is and who she can be and has therefore supported her health and wellbeing.

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• These types of stories can be used to support other young people with similar health and wellbeing issues.

Introduction

Those with physical disabilities are at increased risk of poor physical, psychological and social health including secondary health conditions such as obesity, heart disease and muscle degeneration, mental health conditions such as depression and anxiety and feelings of isolation and abandonment (Richardson, Smith, and Papathomas 2017). However, research has repeatedly shown the physical, mental and social benefits of sport and exercise for disabled people (Darcy and Dowse 2013; Oja et al. 2015; Public Health England 2018; Williams, Smith, and Papathomas 2014). For example, maintaining a healthy weight, improved cardiorespiratory fitness, increased muscle mass and bone density, reduced risk of chronic diseases, increased independence, the development of interpersonal relationships and community connections (Smith et al. 2019). Subsequently many Western/Global North nations have invested in initiatives to promote an active lifestyle among disabled people. In the UK, the context of this paper, the government has invested public monies to facilitate closer working relationships between local government, sport providers and disabled communities as part of its Sporting Futures strategy (HM Government 2015). Yet, more than halfway through the implementation period of this strategy, there has been little impact. Sport England (2018a) reported that 42% of all disabled adults are still doing less than 30-minutes of physical activity per week. This longstanding pattern is concerning given the potential benefits of sport and exercise, but also because the well-documented barriers disabled people face have been accessible to policymakers for some time. These include the physical, social and cognitive demands of competitive sport, a lack of transport, insufficient information or advertising of sport/exercise opportunities, poor access to facilities, sport coaches' lack of understanding of disabled participants' needs and the cost of participation (Jaarsma et al. 2014; Kiuppis 2018; Townsend, Smith, and Cushion 2015; Wright et al. 2019; Spaaij, Magee, and Jeanes 2014). As such there are increasing calls for new insights into what stimulates or prevents disabled people's participation in sport, exercise and physical activity (lves et al. 2021; Jaarsma and Smith 2018; Public Health England 2018). In particular, scholars have called for greater focus on individuals' voices to access the complexities of disabled lives (Brighton and Williams 2018; Wolff and Hums 2018).

Recognising that disabled people are not a homogenous group is key. Individuals' various impairments, illnesses and conditions, needs and abilities will determine their experiences (Noh and Posthuma 1990). Thus, to form clearer and more meaningful understandings of disabled peoples' realities, it is necessary to identify subpopulations whose data will inform our understanding of and for individuals with a particular difficulty (Lumsdaine and Thurston 2017). To date, literature on disabled peoples' *experiences* of sport (and exercise) is dominated by a focus on those who have acquired physical disabilities, particularly men with spinal cord injuries (e.g. Kleiber and Hutchinson 1999; Kehn and Kroll 2009; Martin Ginis, Jörgensen, and Stapleton 2012; Monforte, Smith, and Pérez-Samaniego 2019; Taylor and McGruder 1996; Smith 2008; Sparkes and Smith 2002, 2003). This collection of work has done much to help us understand how people narratively navigate life-changing illnesses and accidents that lead to acquired disabilities. However, the experiences of those with *congenital* physical disabilities, such as cerebral palsy, are marginalised within this context. Indeed, there is a relative absence of children's experiences across disability literature and this needs further attention (Lumsdaine and Thurston 2017; Watson et al. 1999; Watson 2012).

Developmental and psychological work has noted that children with disabilities experience social disadvantages including poorer outcomes in life, psychological and behavioural problems, bullying, low self-esteem and feelings of loneliness and isolation (Blackburn, Spencer, and Read 2010). In addition, despite the known physiological and psycho-social benefits of sport participation (Wickman, Nordlund, and Holm 2018), children and young people with a disability are less likely to take part in sport and exercise than their able-bodied counterparts and the number of children participating is declining (Sport England 2019). They report less enjoyment, feeling less confident and have less understanding of the benefits of why taking part is good for them (Sport England 2018b). Yet, despite these longstanding patterns, their lived experiences or voices are rarely investigated or heard.

A small collection of work has sought to overcome this. Connors and Stalker (2007), Lumsdaine and Thurston (2017) and Watson et al. (1999) all captured children's experiences in and through their research on children and young people with a disability. Children's experiences of sport and exercise were not the focus of these studies. However, Lumsdaine and Thurston (2017) highlight the centrality of sport in the lives of some children with physical disabilities and the positive impact this had on their confidence, self-esteem, personal growth and emotional wellbeing in their broader findings on children's retrospective accounts of growing up with a disability. However, studies on disabled children's experiences of sport and exercise have looked at those with visual impairments (Scally and Lord 2019), intellectual disabilities (Harada and Siperstein 2009; Smith et al. 2015) or various disabilities (Shields and Synnot 2016). In addition, experiential studies often focus on the experiences of parents, families, clinicians and sport development professionals, either instead of or in conjunction with children's views (Foley et al. 2020; Harada and Siperstein 2009; Krops et al. 2018; Shields and Synnot 2016; Smith et al. 2015; Tsai and Fung 2009; Wright et al. 2019). Therefore, the voices of young disabled people, who are so central to understanding

the role of sport in their lives, are rarely heard and even less so in the case of those with congenital physical disabilities such as cerebral palsy. Moreover, across this collection of work surveys and interviews dominate methodologies used to capture young people's experiences. While useful and valid ways of doing research, individuals' data is deconstructed and analysed, and in this process individuals' stories and nuances can become lost (Sparkes and Smith 2014). Thus, the storied experiences of children and young people with congenital, physical disabilities are underexplored, but central to our understanding of the (potential) role and benefit of sport and exercise in their lives.

To address these limitations, we use a narrative approach to examine autoethnographic accounts of a young sportswoman with cerebral palsy as she critically reflects on how competitive sport facilitated her construction of an alternative, healthy self-identity during her childhood and into adulthood. In doing so, our contributions are two-fold. First, we present rich data from a young person with a congenital physical disability, offering autoethnographic accounts of her lived experience of childhood with and without sport. Second, we give *voice* to the fundamental role sport plays in the lives of some young disabled people, adding to physiological, psychological and developmental studies in this area.

Narrative inquiry: a theoretical and methodological framework

Increasingly narrative forms of inquiry offer insight into the lived experiences of people with disabilities (Smith and Sparkes 2008). By assuming individuals are storytelling beings, narrative inquiry is a qualitative tradition that uses stories to understand the 'socio-cultural fabric of lives, subjectivity(ies), feelings, agency and the multi-layered nature of human experience over time and in different sets of circumstances' (Sparkes and Smith 2014, 131). For Frank (2012) a narrative is a socio-culturally derived structure people use to construct the stories they tell and understand the stories they see and hear. Stories, then, are both personal and social and individuals cannot transcend the narrative resources they have available to them within their socio-cultural context (Smith and Sparkes 2009). Thus, by focusing on individuals' stories, researchers gain access to socio-cultural structures that inform, limit and frame individual agency and experience.

By telling stories about ourselves and our lives, or choosing to supress others, we engage in a dynamic process of (re)claiming identities and selves (Smith and Sparkes 2009). Stories 'work *with people, for* people, and always stories work *on* people, affecting what people are able to see as real, as possible, and as worth doing or best avoided' (Frank 2010, 3). Therefore, the narrative resources available in and through the stories we see and hear informs the possibilities and limitations for our future selves and identities (Phoenix and Sparkes 2007). Moreover, narrative is a primary way of accessing our experience of temporality

(Smith and Sparkes 2009). We tell stories of our past, present and future selves and identities. As such, the autoethnographic accounts presented in this paper will inherently offer insight into past, present and future selves and identities, and these are dependent on the narrative resources available and socio-cultural-historical contexts the storyteller is living and has lived through.

Importantly, narratives and storytelling are also embodied (Smith and Sparkes 2009). The physical, fleshy body matters. We use our bodies to engage with the world and the people around us, and to tell stories about our lives. As Smith and Sparkes (2009, 5) state '[S]tories are told about, in, out of, and through the body. The body projects or outfolds its personal, subjective realities...onto other bodies and social spaces. At the same time, narratives out there in society are inscribed or infolded onto bodies'. With this in mind, Smith and Sparkes (2008) make the case that narrative research has great potential for disability studies as the body is both lived and social. Drawing upon the work of (Thomas 2002), they argue that although there are functional limitations on what people with impairments can do, the body can often still share stories about these effects and, in turn, other bodies may relate to and learn from these.

Narrative frameworks have been used previously to understand the experiences of adults with an acquired physical disability, specifically their athletic identity (Perrier et al. 2014), their sense of hope (Smith and Sparkes 2005) and the role of sport and physical activity in promoting posttraumatic growth (Day 2013; Day and Wadey 2016). Notably, Allan et al. (2018) participation narratives from life history interviews with adults (19-73 years old) forms an important basis for our paper. Their work includes accounts from people with congenital physical disabilities, including women and at least one person with cerebral palsy. However, while offering a substantial contribution to our understanding of disabled peoples' experiences of sport and exercise, those with congenital physical disabilities formed a minority of the sample and their accounts were combined and compared with those who had acquired disabilities. The only participation narrative unique to those with congenital physical disabilities - 'from ordinary to extraordinary' - was told by men. Thus, we extend this work by offering further, more focused insight into the lives of children and young people, specifically women, with the congenital physical disability cerebral palsy and the importance of sport in their lives. Using a narrative approach, we sought to address two objectives. First, to identify the types of narrative young people with a congenital physical disability draw upon to make sense of their lives and experiences over time. Second, to examine the role of sport as a means of expanding young people's narrative resources and subsequently their possible future selves and identities.

To frame our analysis we drew upon two of Arthur Frank's (2013) three narratives of injury and illness. Specifically, chaos narratives and quest narratives. A chaos narrative is characterised by despair and loss of hope. Stories framed within a chaos narrative are often hard to hear. They lack a coherent

plotline and are therefore hard to recognise as a 'proper' story, but also our postmodernist context seeks to suppress such stories in favour of restitution narratives, or stories of getting better. In the case of those with congenital physical disabilities though, restitution narratives are not an option. They cannot get better and restore to normative connotations of health. In contrast, then, quest narratives meet suffering head on, accepting impairment and disability and seek to use it. Frank (2013) notes that guest narratives afford the ill person a voice to tell their own story, because, unlike restitution narratives where remedy is the focus, or the chaos narrative that is too painful to tell, there is now a story to tell. He argues there are three facets of quest stories – memoir, manifesto and automythology. Memoirs are typically recollections of past events in relation to the occasion for current storytelling often to offer contrast. Manifestos are almost prophetic and carry demands for social action, often using storytellers' (prior) suffering or difference as a vehicle for change. Finally, automythology is the reinvention of self following a trauma or catastrophic illness.

Notably, the story we present is not one of injury or illness per se, but we propose Frank's (2013) narratives of injury and illness can be used to understand paradigmatic shifts in how young people with a congenital, physical disability understand and experience their world over time. More specifically, we suggest that the narrative resources available in competitive sport offer the potential to enable young people to shift from chaos to quest narratives.

Autoethnography: notes on methodology

The crisis of representation has contributed to a 'narrative turn' in qualitative methods, analysis and reporting (Sparkes 2002a). An autobiographical way of writing, autoethnographies are written in first-person and display multiple layers of consciousness, allowing researchers a means of critically exploring social forces and processes that have shaped their lived experiences (Ellis and Bochner 2000). Autoethnography is an 'approach to research and writing that seeks to describe and systematically analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno)' (Ellis, Adams, and Bochner 2010). It is a means of 'reflexively writing the self into and through the ethnographic text; isolating that space where memory, history, performance, and meaning intersect' (Denzin 2014, 22).

Despite much debate, autoethnography is now widely acknowledged a legitimate and ethical way of doing research that makes scholarship more accessible (Holt 2003; Sparkes 2002b). Allen-Collinson (2012, 205-206), for example, argues that autoethnographers, by sharing their personal lived experiences, provide 'highly readable, insightful and thought-provoking work, vividly bringing alive sub/cultural experiences for those unfamiliar with the social terrain under study'. Similarly, Atkinson (2012) suggests by 'opening

up' autoethnographers help readers to better connect with academic arguments, theories and ideas, thus supporting our understanding of a range of phenomena. However, lone working whilst writing about one's self has been a noted challenge in autoethnographic work, especially within the context of ongoing and inter-linked arguments around self-indulgence and/or lack of self-reflexivity (Winkler 2018), relational ethics and researcher vulnerability (Lapadat 2017). For us, claims of self-indulgence often derive from those who neglect or refute the idea that culture flows from us (Bochner and Ellis 1996) and/or that storytelling gives us access to the socio-cultural fabric that shapes our lives (Sparkes and Smith 2014), but the danger of focusing too much on the personal (auto) and less on the cultural (ethno) and analysis (graphy) is a well-documented concern with this type of work (Winkler 2018). Moreover, the process of academically and publicly reflecting on lived experiences to reveal and analyse socio-cultural phenomena can lead to researcher vulnerability (Winkler 2018). Whereas participants' identities are anonymised in most qualitative research, autoethnographers' publication of their story makes anonymisation difficult, if not impossible. In addition, autoethnographic stories are not wholly our own (Sparkes 2013). They are relational, often telling stories of others in our lives – family members, sport coaches or teammates. So, when autoethnographies explore difficult life events epiphanies, turning points and internal struggles associated with health, wellbeing and self-identities, as is the case with some aspects of this paper - these issues become even more challenging. Indeed, the evocative writing of personal narratives can adversely affect researchers, eliciting strong emotions of unresolved grief or repressed memories (Lapadat 2017). Yet, autoethnography, if done well, not only offers a methodology for advancing knowledge, but can be an empowering and therapeutic progress (Denshire 2014). Increasingly collaborative approaches are offered as a means of overcoming some of these challenges (Winkler 2018). Whilst collaborative autoethnography¹ has emerged as a means of overcoming these ethical and practical challenges (Lapadat 2017; Chang 2013), instead we drew upon recommendations offered by Winkler (2018) and work conducted by Fleming and Fullagar (2007) to work collaboratively to offer an interpretation of the sole autoethnographic accounts of the first author.

The first author and autoethnographer, Gemma, is in her early 20s. Because of being born prematurely, she has cerebral palsy, which affects her mobility and coordination. As such, she has been a full-time wheelchair user from three years old. Now an elite athlete competing in wheelchair rugby at (inter) national level and studying for a Bachelor's degree in Sport Development and Coaching at Abertay University, she, as part of her studies [identifying markers removed for peer-review - she] has autoethnographically captured her experiences of disability in, through and beyond childhood paying particular attention to the role sport (culture) played in the construction of her

self-identity. To achieve this, when writing about her life Gemma critically reflected on different stages and events in her life (both outside of and in sport) and focused more on those events and socio-cultural processes she felt shaped and affected her sense of self and identity. In doing so, her journey through different narratives that shape the lives of young people with disabilities over time was captured. Thus, Gemma is the *storyteller* in and through this paper. Storytelling is notably personal, analytical and theoretical (Frank 2000; Smith and Sparkes 2008). Storytellers choose what stories to tell, which to suppress, how and when they are told, who they tell them to and for what purpose. Therefore, aligned to Denshire's (2014) commentary this was an empowering and therapeutic process for Gemma.

The second author's role was to act in a supervisory context, supporting the (re)crafting of autoethnographic accounts by engaging in reflexive discussions to prompt and expand detail on sociocultural processes within Gemma's story. Indeed, Winkler (2018) argues maintaining a balance between personal storytelling and analysis of culture is challenging even for established and practice autoethnographers, but reviewing individuals' accounts and prompting them to focus more on socio-cultural aspects of their writing where required, is a means of ensuring a balance is maintained. As such, our reflexive discussions were guided by Frank's (2013) work on storytelling as a socio-cultural process and his narratives of injury and illness. This offered a framework for maintaining this balance between auto (personal), ethno (cultural) and graphy (analysis). In addition, the disclosure of wellbeing issues, how these manifested and were experienced were the sources of some reflexive discussions to ensure Gemma was comfortable with sharing the final story in a public domain. Ultimately then, the second author is more of a story analyst than a storyteller (Smith and Sparkes 2008), but in a sense contributed to shaping the story - what and how it was told - via the reflexive writing process. Similar methodological processes have taken place in Fleming and Fullagar (2007) work on women's experiences of cricket participation and management, both of whom conclude this collaborative process of analysing autoethnographic accounts supports telling important and lesser heard stories, particularly in novice autoethnographers.

Hearing the chaos narrative through autoethnography: a life without sport

At the age of 8 I started to feel different to my friends at school. They were all running around in the playground, playing football and I couldn't. This sudden realisation that I was different started to affect every aspect of my life - my friendships, schoolwork and motivation levels. In any situation that involved physical movement, I was very aware that I was different. I relied on my parents to do a lot more for me, more than my friends' parents, like taking me to school when others walked. Even outside of school settings, having a disability was not normal or accepted; it wasn't shown on TV. Para-athletes were only visible once every four years. Even when people with disabilities were shown on TV or in movies, there was an heir of pity and helplessness. My mental health deteriorated quite quickly at this point. I started to isolate myself from other people. I felt so different. This then developed into me stopping doing normal activities such as eating, socialising, going to school. I became phobic about going outside of the house. I couldn't face the thought of people looking at me, because I was in a wheelchair. When I did go out of the house, I used to wear a hat and glasses so I couldn't see anyone looking at me. I received professional help at the time but I hated myself and my disability so much that I didn't see a future for myself. I lived in a bubble to avoid reality, as it was too painful.

Frank (2013) argues chaos narratives are too painful for individuals living and experiencing them to tell. They are often told at a distance, retrospectively and reflexively (Frank 2013). Therefore, in the intersection of memory, history, performance and meaning that comes with reflexive autoethnographic writing (Denzin 2014) we can hear Gemma's chaos narrative. Arguably and importantly, it is only within the broader quest memoir being told in and through the reflexive autoethnographic writing process that we get access to this chaos narrative, characterised by feelings of despair, hopelessness and lack of optimism.

Gemma's chaos narrative gives credence, further insight and voice to psychological and developmental debate around the extent to which young people with disabilities experience low self-concept, that is poor self-esteem around their physical appearance, social acceptance and scholastic and physical or athletic competence (Shields et al. 2006; Shields and Synnot 2016). Indeed, in more experiential work, Lumsdaine and Thurston (2017) note that it is not uncommon for children and young people with physical impairments to experience identity issues as they navigate able-bodied hegemony in Western/Global North societies; subsequently they often face multiple challenges to their physical and mental wellbeing. Thus, in taking a narrative approach, Gemma's story gives (further) *voice* to this.

However, what is concerning and underreported in the literature is, first, the age at which this chaos narrative was being experienced (i.e. eight years old). Future work must look at the storied *experiences* of younger children with congenital physical disabilities, moving beyond psychometric data to breathe lived experience into clinicians' understanding and decisions. Second, and connected to this, is the lack of healthy narrative resources for young people with congenital physical disabilities to draw upon and engage with. The storied narratives of disabled people Gemma engaged with aged eight years old were ones of helplessness and pity. This was not uncommon in media portrayals of disabled people in the early-mid 2000s (Farnall and Smith 1999). Indeed, media continue to produce a meta-narrative of ableism and/or an able-bodied hegemony in Western/Global North societies, that is 'a world that does not value and is not designed for disabled people' (lves

et al. 2021, 3). Moreover, Gemma's story is shaped by a restrictive able-bodied narrative that dominates all levels of sport, exercise and physical activity (Spaaij, Magee, and Jeanes 2014) leading to well-documented social barriers for and lower levels of participation in disabled people (Jaarsma et al. 2014). Children's experiences in particular are often restricted by a lack of access to appropriately adapted equipment, facilities and those with limited knowledge on how to adapt activity (Wright et al. 2019) albeit in this case less formal physical activity and exercise in school settings.

People cannot transcend the narrative resources that are culturally available to them (Smith and Sparkes 2009). If young disabled people do not hear and see positive, realistic stories, then they have very limited to no narrative resources to inform their possible (healthy) future selves and identities. Gemma's story indicates a lack of narrative resources to (re)construct a meaningful, healthy sense of self are likely to result in a chaos narrative being drawn upon and experienced, and this has serious implications for the health and wellbeing of young people with disabilities.

Gemma's chaos narrative also offers possible insight into low uptake of sport and exercise opportunities among disabled people and their lack of enthusiasm for sport (Sport England 2018b, 2019). Aged eight, in the mid-2000s, she had no sustainable narrative resources to inform the construction of a healthy, athletic identity. She notes the visibility of para-athletes was too infrequent and brief to be meaningful for her, at least at this age. This too has been noted by scholars who have examined the effectiveness of para mega-events, such as the Paralympics, and media portrayal of disabled athletes who are famed for embodying the now dominant, yet problematic, 'supercrip' narrative of heroic overcoming of disabled adversity (Brittain 2012; Brown and Pappous 2021; Rees, Robinson, and Shields 2019). Thus, much like Allan et al. (2018) we call for policymakers and sport development practitioners to urgently expand the narrative resources available to young disabled people. This must move beyond the now dominant 'supercrip' or 'superhuman' narrative to allow diverse and accessible storied narratives for young disabled people to draw upon in their construction of possible future, healthy, if not athletic, selves and identities.

Shifting the narrative through sport and living a quest for an alternative self

I got involved in Dundee Dragons Wheelchair Sports Club at the age of 16. This was a substantial turning point for me. I was in a hospital waiting room about to go to an appointment when my mum pointed out a poster for a local wheelchair sports club taster day. I wasn't very keen, but my mum pushed me to go. I think she thought being around other wheelchair users would help me feel less isolated. My self-esteem was still very low and I was worried about meeting new people and making a fool out of myself. When I arrived at the session, I saw wheelchair users who were completely independent, even driving which amazed me! I continued attending the club after the taster session and although I wasn't very good at many of the skills like catching, passing or moving my chair, for the first time in a long time I felt motivated to improve and work towards something.

Not long after I'd started, out of the blue I received a phone call from the Wheelchair Basketball Development officer. She had been in contact with Dragons to see if there was anyone under the age of 19 who played rugby league and might be good enough to compete at wheelchair basketball for Scotland in the Sainsbury's School Games. It was three weeks before the competition and I had never played a game of basketball in my life. I remember thinking this was such a terrifying prospect, but a fantastic opportunity to represent my country and experience something new that I couldn't not go for it! So I did. Three weeks later, I was on a bus to Sheffield about to play my first game of wheelchair basketball and I was competing for my country.

The tournament was unlike anything I had ever witnessed before. It totally changed my perspective on disability, from a negative to a positive thing, I saw young people who were driving cars, going to university. They had trendy wheelchairs and were living life to the full. I thought to myself, I want to be like that, that could be me.

The School Games changed me. It made me want to become independent. Everyone else did things like push their own sports chairs, carry their own bags and push up huge hills without any help. I wouldn't have attempted to do these things myself and would have relied on someone to help me, but I started to try do things for myself for the first time!

After the tournament, I started to play basketball and I fell in love with the sport. After so many years of feeling like an outsider, I finally felt a sense of belonging, which stemmed from being part of a team and feeling accepted and valued within the group. I developed a positive sense of identity for the first time in a long time. I now identified as an athlete - strong, successful, respected. Not a fragile disabled girl in a wheelchair who everyone felt sorry for.

For Gemma, competitive sport enabled a shift from a chaos to quest narrative and this has been reported in other narrative research on participation in disability sport (Allan et al. 2018; Williams 2018), albeit these studies heavily report the experiences of men with spinal cord injuries in this regard. So, while Allan et al. (2018) participants report narratives of 'letting go' of a previously able-bodied reality, including participation in mainstream sport, our work suggests those with congenital physical disabilities experience this narrative shift very differently.

Frank (2013, 117) states 'quest stories tell of searching for alternative ways of being ill. As the ill person gradually realises a sense of purpose, the idea that illness has been a journey emerges'. Moreover, what is being quested is never wholly clear, but is defined by the storyteller's belief that something

is to be gained from their experience (Frank 2013). Gemma's story is not one of illness, but in questing for alternative ways of being disabled, through sport participation in this case, her journey for an alternative self-identity begins. Notably, at the outset of her journey, she is still living in and through chaos, reluctant and sceptical about the journey she later took. In this sense, what exactly she is searching for by initially participating in sport is not wholly clear. It is only the reflexive process of autoethnographic writing that makes this clear. Ultimately though, similar to the findings of Lumsdaine and Thurston (2017) whose work focused on the experiences of children as they grow up with a mobility disability, Gemma's narrative shift was facilitated by participation in competitive sport, more so than other aspects of her life as a teenager. Wheelchair basketball was a socio-cultural space that enabled her access to alternative, posthuman narrative resources to form a new, healthier and athletic self-identity, one that addressed the sense of hopelessness, isolation and difference she was experiencing in and through her chaos narrative. Posthuman narratives show and tell the acceptance of cyborg connections as unavoidably present in the lives of people with mobility impairments and thus a harmonisation or celebration of their agency within the posthuman condition (Monforte, Smith, and Pérez-Samaniego 2019). For Gemma, these narrative resources were so powerful, her quest narrative become automythological, a reinvention of her self (Frank 2013).

The problem then is not that posthuman narrative resources for healthy self-identities do not exist. They have been identified in this, and other similar work (Allan et al. 2018), but what is clear from Gemma's story is that they are rarely heard or seen in the everyday lives of young people and children with disabilities. For Gemma, competitive sport offered a unique and positive space in which healthy storied narratives are lived and offered to others as a resource to (re)construct an alternative, healthy self-identity. Thus in our addition to our, and others (Allan et al. 2018), earlier argument for the expansion of narrative resources, the spaces in which existing meaningful narratives are performed and told also need to either be extended and/or those where they are already told need to be more readily and easily accessed. Sport and community development officers, for example, might, and we argue should, draw upon the importance of these narratives for those with disabilities when designing and seeking funding for sport-based initiatives.

Just as stories are both personal and cultural, they are also relational (Lapadat 2017; Smith and Sparkes 2009) and the role of others in Gemma's story is clear, most notably that of her mother and those at her and other sport clubs - organisers (e.g. coaches and sport development officers) and athletes. Without her mother's spotting of the advert and coaxing to take part, she would not have accessed sport spaces at all. Coaches and sport development officers were also key to her experience(s) and expanding the narrative resources she was exposed to in sport spaces outside of her local

club. Parental, clinician and sport development officers' experiences have been reported in disability sport studies (Foley et al. 2020; Tsai and Fung 2009; Wright et al. 2019). However, Gemma's autoethnographic account highlights the importance of these people in promoting and facilitating opportunities for young people with a disability. They were integral her beginning and maintaining sport participation and subsequently her access to alternative narrative resources which (re)shaped her self-identity and led to an automythological quest narrative (Frank 2013). This gives weight to our recommendations for narrative expansion to be driven by sport development officers and coaches.

Continued quest through leadership in sport: towards a manifesto

Over the next few years, I gained the role of Captain, which increased my confidence. I was given responsibility, a leadership role. My coach felt I had a natural ability to lead and I was empathetic with other players and they could approach me. She encouraged me to take on more responsibility. It reinforced my identity as a basketballer. It was another reminder that I belonged and I was respected.

As my playing career developed so did my confidence in my athletic and physical abilities. I did however transition to wheelchair rugby. The sport is more suited to my impairment level; it is designed for people with upper limb impairments. As a result, I have more opportunity to progress to elite level in the sport compared to basketball. I am currently playing for the GB Talent Team, which helps to prepare athletes for elite (Paralympic level) squads. I am also coaching at the Dragons. I started by taking warm up activities and then small groups. My club saw this as an opportunity for me to become a role model and support younger children with physical disabilities. I was and am still keen to do this. I want to give back to the sport, that gave so much to me, but also to help others have a positive experience. I try to share my passion for sport and try to help others to accept themselves and their disability. Disability Sport has been life changing for me. It has given me a purpose in life and given me a sense of belonging and a future, which looks bright, something that I didn't think was possible during my darkest days. My experiences growing up have inspired me to help others who are dealing with similar issues around identity and acceptance and sport is a means of doing that.

As Gemma's quest narrative moves through time, we begin to access more of her present and future self-identity. Leadership roles in sport, most notably coaching and (inter)national representation, have confirmed Gemma's athletic identity, enabling her to suppress chaos, continue her quest narrative over time and also support others by living in and through and telling her quest storied narrative. Frank (2013) suggests quest stories often embody an ethical, communicative practice whereby storytellers, in acceptance of their contingency or, in the case of this paper disability, seek to support others as they

experience their own contingent realities. Thus, through telling and performing quest narratives, storytellers such as Gemma offer a narrative resource others can internalise and draw upon to (re)shape their own self-identity. Whilst also a continuation of automythology, this communicative practice also serves as an emerging manifesto. Frank (2013, 122) argues that manifestos assert that illness, or in this case disability, is 'a social issue, not simply a personal affliction...society has added to physical problems that disease [disability] entails, and it calls for change, based on solidarity of [and we would add for] the afflicted'. They are often less subtle than other facets of guest narratives and are almost prophetic in their demands for social action (Frank 2013). The autoethnographic process has produced what might appear to be a more subtle call for action. However, in acts of storytelling, storytellers are analysts of their own lives (Smith and Sparkes 2008). They choose which stories to tell, which to supress, how and when they are told and whom they tell them to. By choosing to tell stories about sport and the effect this had and continues to have on her life, Gemma produces a manifesto. Specifically, she is calling for the increased visibility and sharing of sport-based storied narratives in, through and beyond sport so they might act as a potential resource for reshaping individuals' lives as they grapple with the dominant metanarrative of ableism in Western/Global North societies.

Conclusions

Our narrative approach has demonstrated the benefit and role of sport in the lives of young people with congenital physical disabilities. Sport spaces and the alternative, lived narratives within them offer healthy resources for those with congenital physical disabilities who often face challenges to their physical and mental wellbeing as they navigate a world of able-bodied hegemony. Moreover, Gemma's autoethnographic accounts of lived experience without, in and through disability sport gives *voice* to the wealth of physiological, developmental and psychological knowledge on the benefits of sport for disabled people. Thus, we answer calls to focus on the voices of disabled people to further knowledge on the complexities of their participation in sport (Brighton and Williams 2018; Wolff and Hums 2018).

The posthumanist narratives available in disability sport offer alternative and healthy resources for young people with a congenital physical disability who are struggling with growing up an able-bodied hegemony. Gemma's story, in particular her shift from a chaos narrative to a sustained quest, shows the power of such narratives and sport spaces, which enable them to be experienced. As such we support calls for the expansion of these narratives (Allan et al. 2018), but also argue further expansion of the spaces in which these narratives are told and shown is also needed. Gemma's story highlights how important parents, coaches and sport development officers are in the lives of children and young people with a physical disability. Therefore, they will be central to this expansion. If stories, and the narrative structures within them, 'work *with people, for* people and...*on* people, affecting what people are able to see as real [and], as possible' (Frank 2010, 3) the sport-based, healthy and alternative storied lives of young people with a disability need to be shared more broadly. Sport and community development officers, for example, should look to use stories when designing, advertising and even seeking funding for their projects. To do so offers two-fold benefits. First, to provide much needed storied resources for disabled children and their parents. Second, to offer others, including those who are able-bodied, a glimpse of life from a different perspective (Frank 2000) which in turn might reduce the social barriers people with disabilities face in their day-to-day lives.

While offering *a* voice, Gemma's story is not definitive of all young people with a congenital physical disability many of whom are likely to experience sport spaces and the narratives within them very differently. We therefore propose that the narrative turn in social research on disability might be utilised further to explore others' experiences. Autoethnographic work like ours might be one way of doing this. Collaborative autoethnography (see Chang, Ngunijiri, and Hernandez 2012), whereby researchers collectively 'analyse and interpret a group's collection of autobiographical writing as well as their own' (Lapadat 2009, 967) might also offer a way of extending our work.

Note

 Collaborative autoethnography comes in various forms and has various names (e.g., duoethnography, co-constructed autoethnography, co-ethnography), but we interpret this to be where researchers 'analyse and interpret a group's collection of autobiographical writing as well as their own' (Lapadat 2009, 967). See Chang, Ngunijiri, and Hernandez (2012) for an overview of this work.

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