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Finding 'me' through wheelchair basketball: an autoethnographic study of finding acceptance of a new identity after acquiring a disability through surgical removal of a sacral chondrosarcoma

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ABSTRACT

Purpose: This study explores the first-authors experience of acquiring disability through treatment for sacral chondrosarcoma, a form of primary bone cancer. It examines the psychological, physical, and social impacts of this life-altering illness, particularly identity loss, and how wheelchair basketball, and the community surrounding it, played a transformative role in reshaping and accepting their new disability identity.

Method: An evocative autoethnography approach was used to present subjective, raw, emotional realities to encourage readers' immersion, empathy, and reflection. This method highlights how sport can support identity (re)formation following life-altering illness.

Results: This autoethnography consists of nine short stories detailing the first authors experiences through and beyond cancer treatment. These stories explore the disintegration and reconstruction of identity, culminating in the discovery and acceptance of a new identity through sport.

Conclusions: This evocative autoethnography provides insight into the lived experiences of disability acquired through cancer treatment. It explores identity loss, the transformative power of sport in the (re)discovery of identity, and the nuanced components that intersect to support patients to form new identities post-diagnosis. These stories may resonate with others facing life-altering illness or injury, offering reassurance that (re)discovery of self is possible.

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Primary bone cancer; disability; identity; wheelchair sport; qualitative research

> IMPLICATIONS FOR REHABILITATION

- Acquiring a disability through cancer treatment affects psychological, physical, and social wellbeing, often resulting in a loss of identity.
- Rehabilitation should take a holistic approach, considering long-term challenges such as pain management, body image concerns, and social reintegration.
- Participation in disability sport can support physical recovery, build confidence, and help patients in their acceptance of a new disability identity.
- Although rehabilitation specialists should not prescribe exercise, they should recognise its value and possess the knowledge for how to facilitate participation in sport.

Introduction

Primary bone cancer (PBC), also known as bone sarcoma, is very rare accounting for less than 1% of all new cancer cases in the UK between 2017 and 2019 [1]. On average, there are around 550 people diagnosed with PBC in the UK annually [2]. The most prevalent subtypes include osteosarcoma and Ewing sarcoma, which are more common in children and young adults, and chondrosarcoma, which is more frequently seen in older adults [3]. There has been little progress in improving the five-year overall survival rates for PBC over the past 25–30 years, with rates remaining steady at around 53% to 55% [4].

Although PBC can develop in any bone, it most commonly affects the long bones of the legs and upper arms [5]. The primary treatment for PBC is surgical resection of the affected part of the bone.

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Depending on the subtype, this may be accompanied by chemotherapy or radiotherapy [6]. Limb-sparing surgery, where the bone is reconstructed or replaced, can often be used to remove the affected part of the bone, though in some cases, amputation may be necessary [7]. PBC can also be diagnosed in the spine, although this is rare. For example, a Leeds regional bone tumour registry reported that only 4.6% of all entries between 1958 and 2000 occurred in the spine [8].

Chondrosarcoma, which accounts for approximately 10% of all PBC worldwide, with less than 10% of those occurring in the spine [9], responds poorly to conventional chemotherapy and radiation, and is primarily treated through wide surgical excision [6]. Surgical treatment for chondrosarcomas located in the spine is difficult due to its invasive nature and the proximity to the spinal cord [10]. Recurrence after surgical removal occurs in over one third of patients (33.7%), resulting in the need for additional surgery, and the mortality rate for those diagnosed with a chondrosarcoma is 26.4% [10].

While some PBC patients may complete their primary treatment and regain their previous level of health, function, and wellbeing, a significant number of former cancer patients do not return to their pre-treatment levels of functioning. Instead, due to the invasive nature of the surgery required to remove the tumour, patients experience several challenges following their treatment, which negatively impact their physical function, pain intensity, and quality of life [7,11]. Research has demonstrated that the impact of treatment can interfere with the ability of PBC patients to engage in educational and vocational pursuits and can have a negative impact on their social life and participation in leisure activities [12]. In addition, former cancer patients can experience low mood, anxiety, fatigue, poorer cognitive function, reduced sexual functioning and fertility issues, and changes in body image and identity [7,12]. These effects can persist for months or even years following treatment, or they may emerge many years later. As a result, former PBC patients face significant health challenges and functional impairments as long-term consequences of their treatment [13–15].

Participation in physical activity during and after cancer treatment has been shown to provide multiple benefits, which help to reduce some of the adverse effects of cancer treatment. For example, Campbell et al. [16] demonstrated that participation in physical activity helped to reduce cancer-related fatigue, anxiety, depression, and improve health-related quality of life and physical function in adult cancer survivors. Additionally, a qualitative study by Adamsen et al. [17] found that young cancer patients undergoing chemotherapy, who had previously held an athletic identity, were able to reclaim some of their pre-cancer identity and increase their physical strength through participation in a six-week exercise intervention. However, there is limited literature on participation in physical activity and/or sports in patients who have experienced PBC. Currently, research on physical activity levels of patients with PBC has focused on those who have undergone treatment on lower limbs. For example, Hobusch et al. [18] measured sporting activity in patients with Ewing's sarcoma who had undergone limb salvage surgery for tumours located in their pelvis, femur, tibia, and fibula. Their study found that most participants were able to achieve high levels of sports activity following surgery. In addition, Lang et al. [19] demonstrated that some long-term PBC survivors who had undergone surgery for osteosarcoma above the knee were able to achieve high levels of sports activity. They found that patients' levels of sports activity were influenced by their pre-operative level of activity.

To the best of my knowledge, there have been no studies examining participation in physical activity and/or sport in patients with spinal PBC. This paper addresses that gap through an evocative autoethnographic account of my cancer journey, focusing on how disability acquired through surgical treatment disrupted my sense of identity and how participation in wheelchair basketball facilitated the construction and acceptance of a new disability identity. The paper is written in the first person, with my (the first author) lived experience forming the basis of the autoethnography; co-authors contributed by providing methodological guidance, dialogic reflection, acting as critical friends throughout the writing process, and supporting the development of the manuscript.

I was diagnosed with a sacral chondrosarcoma, something that occurs in only 5% of those diagnosed with this subtype of PBC [20]. Over nearly six years, I underwent four major surgeries, each resulting in a progressive worsening of disability. Through a series of narrative vignettes presented in chronological order, I describe my identity prior to my diagnosis (Story 1), followed by the physical, psychological, and social impacts of cancer treatment, including diagnosis (Story 2), worsening disability (Story 3), chronic

pain (Story 4), weight gain (Story 5), and anxiety (Story 6), and how these experiences disrupted and reshaped my identity over time. I then explore the transformative role of participating in sport, specifically wheelchair basketball, in reconstructing my sense of self and facilitating acceptance of who I have become (Story 7). Finally, I reflect on two instances of misidentification, first as a military veteran (Story 8) and later as someone aspiring to be a Paralympian (Story 9), and the impact these encounters had on my developing disability identity. By sharing my lived experience, I hope to provide insight for those working in National Governing Bodies (NGBs), healthcare, and education into the importance of promoting and facilitating sports participation for individuals with life-altering illness and disabilities.

Methodology

The philosophical assumptions that underpinned this study were ontological relativism (i.e., reality is multiple, created, and mind-dependent) and epistemological constructionism (i.e., knowledge is subjective and socially constructed) [21]. Consistent with these assumptions, autoethnography was selected as the methodological approach. Autoethnography is a qualitative research approach that seeks to describe and systematically analyse ('graphy') personal experience ('auto') grounded within the experienced culture ('ethno') [22,23]. Autoethnography allows the researcher to explicitly situate and 'write in' themselves as a central figure in their research and portray their own personal, lived experience of a culture [24].

Autoethnography was chosen, as it acknowledges and embraces subjectivity, emotionality, and the researcher's influence on research, rather than pretending they do not exist [25]. Although the experiences presented in this manuscript may not be universally shared, they are intended to engage readers on an emotional and empathetic level through evocative writing. In doing so, this study aims to form a sense of connection, relevance, and resonance with readers' own experiences [24]. For those experiencing life changing illness or disability, it is hoped that the narratives shared in this paper illustrate that a meaningful life and positive identity remain possible following such experiences.

More specifically, I adopted evocative autoethnography to reflect on key stages of my cancer experience. Evocative autoethnography seeks to create an emotional response from readers by showing rather than telling, using emotionally driven narratives to allow stories to do the theoretical work rather than the researcher providing explicit analysis or telling readers what the stories are meant to theoretically convey [26,27]. This approach has been used in previous autoethnographies examining athletes with disabilities experiences of participation in sport, such as Deaf athletes [28]. Evocative autoethnography contrasts with analytic autoethnography (e.g., 29), a form that typically emphasises systematic analysis and theory-building. The purpose of analytic autoethnography is:

"Not simply to document personal experience, to provide an "insider's perspective," or to evoke emotional resonance with the reader. Rather, the defining characteristic of analytic social science is to use empirical data to gain insight into some broader set of social phenomena than those provided by the data themselves." [30, pp. 386-387].

I was inspired to write and share my stories after reading several autoethnographies related to disability and sport (e.g., 28,29). Reading other stories made me reflect on my own experiences and having initially started with jotting down a few sentences, I started to realise that writing my story was therapeutic, and I felt compelled to write more. I hope that by sharing my journey, others will feel liberated to give voice to their own experiences. Given the aims of this paper, evocative autoethnography was deemed to be the most appropriate approach to use and was necessary in keeping the authenticity of the story intact.

As the storyteller in and through this paper, I have chosen what stories of my treatment to tell, which to suppress, how and when they are told, and who I tell them to and for what purpose. The narratives presented trace my journey from life before diagnosis (Story 1), through nearly six years of cancer treatment and four major surgeries, to reconstructing my sense of self through participation in disability sport, particularly wheelchair basketball (Stories 2–7). Finally, I describe two instances of being misidentified (Stories 8 and 9), and the impact that these encounters had on my developing disability identity. Throughout, I reflect on the events and socio-cultural processes that shaped my sense of self and identity, capturing the diverse narratives that defined my life as both a patient and survivor.

Results

Story 1: Prelude

"If anyone needs a crutch, then I need a wheelchair" (Lyrics from 'In Remission' by The Menzingers)

I have two passions in life. Music is my main love, but this is closely followed by my love of football (particularly the mighty Arsenal – come on you Gunners!). Growing up in the late 80s and early 90s, my friends and I were obsessive Arsenal supporters. We started to attend matches at Highbury (home of the Gunners pre-2006) as often as possible towards the end of our time at primary school at the age of 11 years. I idolised those players; Tony Adams, Paul Merson, and Ian Wright were my favourites.

However, when it came to *playing* football, while I was very enthusiastic, I possessed very little skill. When my primary school participated in a UK Football Association (FA) skills programme – an initiative designed to help kids aged 5 to 11 years develop their football skills – I was only awarded one star out of five, thus reflecting my lack of ability. This didn't put me off though, and I played football as often as I could throughout secondary school.

In 1994, my life changed. I discovered music! Bands such as Blur, Oasis, Nirvana, Pearl Jam, and Rage Against the Machine resulted in music becoming the biggest thing in my life. I took down all my football posters, Mr. Arsenal, Merse and Wrighty, and slowly covered my bedroom (walls *and* ceiling) in posters and magazine clippings of my favourite bands. My love for music and bands like NOFX, The Offspring, and Sonic Youth led to me wanting to learn to skateboard after it was featured in their music videos – not impressionable at all!

I got my first skateboard on my 14th birthday and, with my new group of 'alternative' friends, spent all our time either listening to new albums, watching music videos, or skateboarding. While my room's previously red décor had been replaced as the motif for the 90s grunge scene, I still loved and played football for my secondary school team and had joined a local boys club. I was, however, deemed the 'weird' kid – turning up to matches on my skateboard, wearing a Nirvana t-shirt and carrying my kit in a canvas army bag – the 90s teenage mind could apparently only let you be part of one social group. I was the outsider of the team – I identified as a footballer and a 'grunger'.

After leaving secondary school at the age of 18 years, and a very short but very drunken stint at university, I started working at a Virgin Megastore in my hometown. For readers born after 2007, a Virgin Megastore was a place you could go and physically buy music. As a music obsessive (it was my dream job!), my friends and I spent most weekends in London watching bands, we drank in the local 'alternative' pub, and the Arsenal still played at Highbury – life was great.

During this time, my then girlfriend and I decided to go away for a season snowboarding in France. We booked our accommodation for the season at the end of the following year and, alongside my day job at Virgin Megastore, I took up an evening shelf stacking job in a supermarket to save money. It was now mid-to-late 2000, and when I first started to feel a pain going down my left leg. It started as intermittent but gradually got worse to the point that I would often end up crumpled on the floor in agony. One of my most vivid memories of this time was going in for a tackle whilst playing in a local five-a-side football league and feeling an immense white hot shooting pain when I made contact between the ball and the other player. Laying on the floor in agony thinking that I had broken something, I was completely unaware that the cause of my pain was something much worse, was going to completely change my life, and lead to me losing all sense of who I was. This is my story.

Story 2: My diagnosis

You have a sacral chondrosarcoma. That is a rare form of cancer for someone of your age and is in an even rarer place in your body.

This is what the consultant said to me when he first told me about my cancer diagnosis. The only thing he didn't do was produce a medal congratulating me for the type and location of my cancer. It was the end of August 2001, and this was the start of a nearly six-year cancer journey and the journey into my disabled identity. I was twenty years old and couldn't digest that I was being diagnosed with cancer. I thought I was an athletic and fit person (despite smoking and drinking too much) and that I was far too

young to be getting cancer. Although I was completely blindsided by the news, there was also a sense of relief as my GP (General Practitioner) had been dismissing my symptoms for nine months prior to my diagnosis and kept telling me that I had sciatica due to the sharp stabbing pain I was getting down my left leg. Having booked the snowboarding season in France, I had gone to my GP so that whatever was going on could be nipped in the bud before the season started. Despite a tennis ball sized lump now protruding from my lower back and only being able to sleep by laying on my front across two beanbags (I think that this arched my back and stopped the tumour from pressing on my sciatic nerve), my GP had refused to send me for any scans. It was only because my mum knew a consultant through her job as a receptionist at our local A&E department that I was able to have my initial MRI scan. Although the news was devastating, at least I was vindicated in knowing something wasn't quite right.

Story 3: My new norm ... then another ... and another ... and another

In September 2001, just over two weeks after my diagnosis, I underwent the first of four major surgeries to remove the tumour. My subsequent surgeries took place in December 2003, January 2005, and January 2007. Due to the location of my tumour, every surgery I had resulted in more nerves being severed and left me having to (re)learn how to live my life with a different, more significant disability. The psychological impact of all this was the single most difficult part of my journey. After a two-year re-emergence of my tumour, I had to start from the beginning...again, just as I was adjusting to the new demands of my disabled body.

After the first surgery I had a dropped left foot which I quickly adapted to – though I found out I couldn't skateboard anymore when I faceplanted the pavement whilst trying to run off my board downhill. That's skateboarding gone.

I had to wait nearly a year for my second surgery after my consultant decided that he would look for an alternative treatment and then admitted to putting my notes to the bottom of the pile as he didn't know what to do. A change of hospital and consultant later, a tumour that could have been "*cherry-picked*" (my new consultants' words) required a much bigger surgery to remove. This surgery resulted in my left leg being completely numb and unresponsive and I could only mobilise using crutches. I really struggled with this as I wasn't confident using crutches and worried about falling over all the time. I barely went out at this point, spending my time either at home or at my then girlfriends' parents' house. In a cruel irony this was midway through Arsenal's 'The Invincibles' season, so, while my team were unstoppable, I had all but stopped. However, bigger changes were to come - the third surgery would be the most severe.

In December 2004, having spent the last week trying to enjoy the Christmas period knowing that I had another surgery coming up, I received a surprise phone call asking me to come into the hospital as my consultant wanted to discuss the plans for my surgery. My parents and I were called into a room where we sat in front of my consultant and Macmillan (specialist cancer) nurse. I was told that I needed a hindquarter amputation and hemipelvectomy. They explained that to have the best chance of completely removing the tumour, they needed to approach it from below as well as through my back. This meant that my left leg would be completely amputated, and the left half of my pelvis would be removed. I spent the next four days in a complete daze and with no time to compute the enormity of the surgery. Little was I to know that an already huge, risky surgery, would result in pretty serious complications.

I had the surgery in January 2005. It went drastically wrong. I had an uncontrollable bleed which caused a heart attack. The surgeon ended up packing my wound, I was placed in an induced coma and taken to the intensive care unit (ICU). Soon after, my organs started failing. The surgeon informed my family that I needed to be taken back down to theatre the next morning and there was a good chance I would not survive. I'm told my whole family visited me that evening to say their goodbyes.

The next day I was taken back down to theatre to have the packing removed and the surgery completed, if I survived. I have a vivid memory of my Great Grandad (who had died on my 18th birthday) coming to me and telling me to keep fighting as I had a whole life to live. I obviously paid attention to what he said, as I made it through the surgery. I then spent a fortnight in a coma and, after coming round, I had such severe hallucinations that my family asked if I would ever be okay again. These hallucinations ranged from snipers trying to shoot me from the rooftop (my only 'military experience!'), to watching Red Hot Chilli Peppers live (that was pretty cool!), to accusing my sister and then girlfriend of

'getting their titties out' for page 3 of The Sun newspaper (...no idea). Due to the hallucinations, I was placed under the psychiatric team so they could monitor my recovery from the coma. I remember being visited by a psychiatrist a few times after I was moved from ICU to the orthopaedic ward to see how I was recovering after the hallucinations. I was never offered any long-term mental health support from the hospital to help me process everything after the complications of having my amputation. However, looking back, I am not sure I would have been able to verbalise the emotions I felt after such a traumatic period of my life.

My amputation was the hardest surgery to recover from mentally as not only was I aware that I had nearly died, but I was now 'wheelchair bound' and very visibly different to everyone I knew. As a way of trying to make myself feel more 'normal', I attended an amputee physiotherapy clinic at my local hospital twice a week, determined that I would learn to mobilise using crutches. However, due to the damage caused by three surgeries, my spine was so weak that it couldn't support me whilst standing using a walking frame let alone crutches. At the end of 2006, my consultant decided that I needed to have rods put in to help stabilise my spine, with the hope that this would enable me to use crutches. Unfortunately, during the MRI scan for planning the surgery they saw that the tumour had returned [rereading this, I have noticed how little I make of this news – I think that, by this point, I was so used to receiving bad news that it didn't seem like such a big deal anymore – another tumour? Sure, why not?!]. The final surgery cemented my position as a wheelchair user as the nerves for my right leg were severed, with my consultant commenting "*oh, you won't walk again cause your right leg is paralysed,*" with all the informality of commenting on the weather outside.

I have vivid, traumatic memories of the recovery from each surgery, especially of having to be turned on my side to reduce the risk of pressure sores. Every time this happened it felt like I was being ripped in two due to the pain, and despite my screams of agony and protestations, this process was repeated multiple times daily. By the end of my cancer journey, I had absolutely no idea who I was anymore. I had completely lost all sense of the Adam I once was and was devastated that this was how my life had turned out.

Before I was diagnosed with cancer, I would have considered myself a passionate, if somewhat amateur, sportsman. I had always loved playing football, skateboarded at a very basic level, had planned on developing my snowboarding skills during my season away, and I cycled everywhere. To this day, the freedom of riding my bike is the thing I miss the most from my pre-cancer life (very ironic for someone who now spends their life on wheels!).

Story 4: Welcome to the world, 'Frank the Fuckbot'

It's 5am and I've been awake with stabbing pain since 1.30am. I've got to be up at 7am so I can get to work but I'm not entirely sure how I'm going to function to move, let alone teach statistics to first year undergrads. Neuropathic and phantom limb pain are a daily occurrence for me. It's not always so intense that I can't sleep, but it is always there and is the thing that disables me the most. I've called this part of my identity 'Frank the Fuckbot', my pain alter ego. A cigar smoking Pablo Escobar type character. He wears steel toe-capped boots to frequently kick me in the shins (one which is not there and one which I can't feel) and carries a cattle prod which he jabs me with 24/7. Frank impacted my life before I was even diagnosed with a chondrosarcoma. Like a gestation period, for the nine months leading up to my diagnosis my 'sciatic' pain got so bad that I couldn't sleep, and I would frequently end up crumpled up on the floor at work. After being born, Frank slowly grew over my first two surgeries, became fully formed after my amputation, and then 'powered up' with the last surgery to remove my tumour. Since then, he has loomed over me like a sinister, dark shadow. Some days he has minimal impact on my daily functioning but, if he's in a particularly sinister mood, like tonight, he can stop me from sleeping, stop me getting out of bed, stop me functioning, thinking, living. When he's at his worst, my wife lovingly stroking my hair can lead to me screaming out in agony. I hate him and how he has this much impact on my life.

From my second surgery onwards, my medical team prescribed a variety of different medications to try and control Frank. This included trying fentanyl patches, followed by methadone, before finally settling on oxycodone – you know, nothing too strong. These three medications often left me in a

zombie-like state without having any effect on my pain. Before a new medication could be introduced, I would have to come off the one I was currently on. The worst experience was changing from fentanyl patches to methadone as it was done over the course of one weekend. I was told to stop using the fentanyl patches on the Friday and had been booked into my local hospice (who were helping with my pain management) to start taking the methadone on Monday morning. This process resulted in a state not unlike that shown when Ewan McGregor's character 'Mark Renton' goes cold turkey when withdrawing from heroin in *Trainspotting*. Along with cold sweats and nausea, I had to deal with Frank's increasing presence over the weekend, resulting in sleep deprivation and hallucinations (again!). The whole experience left me feeling like I had been let down by the hospice and my GP, as they should have helped me go through the withdrawal process as an in-patient and not leave me to do it at home.

Needless to say, I have never rushed coming off a medication again. Unfortunately, it took me around 17 years to decide that I didn't want to take any form of opiates and to just stick to medications designed for neuropathic pain. It feels like Frank deprived me of being able to live in the moment during those 17 years as I always felt slightly out of it and was not always aware of my surroundings. Although my current mix of medications isn't perfect, it does help lessen Frank's control over my life. I have also learnt over the years that he will always be a part of who I am and that I need to be better at recognising when I need to rest to reduce how much he dictates my life.

Story 5: Who's that fat man that ate adam?

Could you go and get the extra-large strap please?

I clearly remember these words being spoken by my nurse. They were a hot knife of embarrassment skewering through my chest. These words triggered the sudden realisation of how much weight I had put on. I could not understand how I had gotten so far away from the athletic person I was before my cancer journey. It's been over three years since I had the final surgery to remove my tumour, and I am back in hospital having a 'pressure sore' treated. The nurse needs to weigh me before I go to theatre to have the wound cleaned and debrided (again!) but the usual strap we'd used for the hoist previously is now too small. I have been admitted to hospital multiple times over the last three years for this treatment, and despite having vacuum pump therapy, the 'pressure sore' won't heal. It turned out in the end that it wasn't a pressure sore. Rather, a sharp piece of bone had been missed during my final surgery to remove the tumour and had caused a deep lying infection in my right bum cheek. Despite my district nurses saying from the beginning that it wasn't a pressure sore, it took until 2011 for a consultant to listen and for the issue to be resolved. The fact that I nearly died after my amputation means that I now have full-blown panic attacks every time I go down to theatre, each trip further devastating my already fragile mental health. At the consultants' request, I have been on bed rest for a year prior to this admittance. This has also deteriorated my mental health to the point that I am having panic attacks every morning which result in me being physically sick. As well as coping with the fallout of my own cancer treatment, I am also having to deal with my mum being recently diagnosed with breast cancer. What a family inheritance!

My mum was always the strong one during my cancer journey. She kept the whole family going. I want to do the same for her, but I don't think I've got the capacity to be that person now. Whilst off work undergoing her treatment, my mum has become a feeder, bringing me three meals in bed every day and buying me lots of treats. I don't compute that lots of food whilst being bed bound will result in me putting on weight. I just eat to make me feel better.

The nurse weighs me, and I am twenty stone. Fuck. That is nine stone heavier than I ever was before this all started. I thought coping with six years of cancer treatment would be the hardest thing I'd ever have to do, but the effects of the last three years and learning that I am now obese is absolute hell!

I've since learnt that, during this time, my family would replace my goldfish when they died as they were so worried about my mental state - they thought learning a fish died would tip me over the edge. I can laugh about this now, but it certainly helps to cement just how dark a place I was in at this stage.

Story 6: Anxieties, old and new

Run Forrest, run!

This is what was shouted at me as I wheeled down a hill whilst playing with some children at a wedding. I was already anxious about leaving the house in my wheelchair and would only go out if someone was with me. Even then, I would wear a baseball cap and hide underneath it, not looking anyone in the eye. Now, that anxiety has been vindicated by a throwaway comment from someone I don't even know, and someone who can't even use a quote correctly as I clearly can't run!

Anxiety isn't new to me; I've always fidgeted and worried about what others think of me. I'm good at being on the periphery of what's going on, only building up the courage to join in once I've 'figured' everyone out. I guess this is my cliched reason for being interested in psychology and understanding what makes people 'tick'. My anxiety has been heightened since I have been a wheelchair user. I am constantly worried about what people think about me and cannot stand seeing footage of me wheeling in my wheelchair. I am also a nervous wheelchair user. I do not like being pushed and always want to be in control of my chair. For some reason, people assume that they can just come up behind a wheelchair and start to push you without warning. This has resulted in me having arguments with random members of the public. Unfortunately, when you have very limited core control, it doesn't take much to cause you to fall out of your chair. In 2021, my anxiety was proven to be warranted.

Wheeling down the pavement, I caught the edge of a drain cover with my front caster wheel and flew out of my chair in Superman like fashion. If you had been walking down the pavement and hit the same drain cover, you would probably look back and wonder what had caused you to stumble. Unfortunately, this was not the case for me. As my wheelchair stopped dead, the momentum of my body caused me to come out, my leg then buckled underneath me, and my body came down on top of it resulting in a broken tibia. The realisation that I had actually broken my leg only occurred later when I could hear the bones crunching whilst lifting my leg to get my trousers on.

This anxiety around a lack of control is not a new one. When I was learning to skateboard during the 90s, I was unable to do any tricks that involved jumping with my board whilst it was moving. My brain is always thinking through what the negative consequences of my actions could be. This meant that I was happy to do ollies (jumping with my board) whilst standing still but if you asked me to do it moving over a wall, my brain would flick a switch which stopped me at the point of hitting the wall and I would chicken out. It is exhausting to cope with anxiety daily. I am always on alert, always looking out for the next thing that could cause me to fall out of my chair or hurt me in another way.

Story 7: Freedom in gliding. Acceptance of me

I'm sat on the side of the basketball court strapping myself into my sports chair. I look around and there are lots of people just like me. There's someone transferring from their day chair into their sports chair, another person taking off their prosthetic legs before getting in their sports chair, and someone walking in with an unusual walking gait. I feel like I am in my community. Fastening up the last of my four straps, I feel secure in my chair and know that, even if I tip over, I am not going to fall out and hurt myself. I wheel onto the court and join in with the first drill, putting up layups. I am useless at shooting and berate myself constantly, frequently getting comments about being too hard on myself; that's anxiety for you. I don't really care though, I feel completely liberated being able to zoom around in my sports chair and leave my anxieties at the side of the court. Playing basketball is also the only time that I don't experience pain. It's almost like I leave 'Frank' behind in my day chair, angrily glaring at me with his cigar, and get a couple of hours respite from his abuse.

I came to wheelchair basketball about seven years after my last cancer surgery and nine years after becoming a full-time wheelchair user. Despite being in a hospital with an amazing spinal cord injury (SCI) unit and a sports hall that was home to one of the best wheelchair basketball teams in the UK, I was never introduced to the sport whilst an in-patient. Due to the nature of my surgeries, I was on the orthopaedic ward of the hospital with all the old people having their hip and knee replacements. None of those involved in my healthcare team seemed to join the dots that, as my surgeries had resulted in

paraplegia and me being a full-time wheelchair user, I would probably have benefitted from not only meeting individuals with SCI, and therefore disabilities like mine, but seeing that it was possible for me to participate in a team sport. Instead, it took a local disability sports club to introduce me to wheelchair basketball.

After a few years of my family telling me about the disability sports club, I finally built-up the courage to go. Attending for the first-time took every ounce of energy I had. I had virtually become a recluse and rarely went out without someone being with me. When I joined, the club only offered solo sports such as archery and target shooting. I took up target shooting but found no relief from my anxiety. I basically sat for an hour firing pellets at a paper target whilst all my anxieties played continuously in my head. Starting to realise that my involvement in target shooting was hugely detrimental to my mental state, I made a decision that was totally out of character with who I was at that point; I approached the Sports Development Manager to see if we could start a wheelchair basketball section at the club. Having played football until my diagnosis, I craved the opportunity to play a team sport again and be involved in a team sports environment.

Originally, there were only three of us that attended training each week, but it slowly grew, and my team-mates became my new family. Through a shared sense of dark humour around our disabilities, I learnt how to accept who I now was. I honestly would not be writing this if I hadn't started playing wheelchair basketball. Through the support of my team-mates, I gained confidence in myself as a human being and started to live my life again. My increased confidence led to me gaining employment at the disability sports club, and this resulted in me realising that I wanted to attend university. One undergraduate degree, postgraduate degree, and doctoral degree later – I am sharing the power of wheelchair basketball!

My participation in wheelchair basketball also helped me to get back to the weight I was before my cancer journey and build-up muscle again. This has been hugely important to me as I could no longer recognise the person I had become. I was a tad vain as a teenager. I did okay with the ladies, and I knew it! Getting to a point where I was happier with my body gave me the confidence to start dating again, which led to me meeting the love of my life, who I married in 2025. My body is still by no means perfect (whose is?). I have excess skin from being obese, one leg, half a pelvis, and spine held up by construction - but I am much happier with who I am.

Story 8: Please don't thank me for my service (unless it's to cancer)

It's 2019 and I'm at Magic Kingdom in Disney World, Florida, waiting to watch the evening firework display. It's been a typically humid July day in Florida, but as dusk sets in, the air starts to cool, providing some reprieve from feeling like I'm breathing in a sauna. All around me, people are jostling to get the best position for watching the evenings display. Exhausted parents laden with the day's purchases are trying hard to keep their equally exhausted children from running off. Loud groups of young adults laugh and push each other in jovial good humour. Interspersing the hum of these groups are sharp shouts from impatient stewards – “*move in! make room!*” – trying to shepherd everyone into the square where the show will begin.

I watch these huddled masses from the vantage point of the ‘handicap pen’ – a rare perk of being a wheelchair user! My fellow ‘handicapped’ posse are positioned behind a brick wall surrounding a beautiful pond that reflects the Disney castle and sporadic fireflies fluttering through the air. My ‘able-bodied’ girlfriend and friend stand behind me, trying not to block other wheelchair users whilst guarding me from kids running rampant so they don't run into my chair and as a result, cause me to have a ‘pain episode’. I look to my left and lock eyes with an old man with white hair, well-worn face, and a Vietnam Veteran cap on. It's like he's been willing me to look at him.

Thank you for your service, son.

A hot mix of embarrassment and annoyance sweeps through my chest. Being thanked for my service has been a regular occurrence throughout my past two holidays to the States. A previous holiday to the Southern States was particularly bad. I was thanked for my service multiple times in

a bar in New Orleans as well as having a very in-depth conversation with a homeless veteran who thought I'd 'get' how his life had fallen apart since serving in the military. Also, while wheeling through a park in Alabama, I was stopped and thanked by a park worker. During my time in Florida, I have already been revered for 'protecting the freedom' of my fellow Americans whilst waiting in line to ride Thunder Mountain. All this is quite a feat for an Englishman that's never been close to joining the armed forces.

I get it. I'm heavily tattooed, short haired, young(ish), athletic looking, and an amputee in a wheelchair. As frustrating as Americans assuming I'm a veteran is, I take time to explain that my disability is the result of cancer and that I've never served in the military. As I turn to correct the old man as I've always done, I stop. I see that he has tears running down his face and he's obviously reliving the horrors that he saw during his time in the military. I choose to stay silent. Thinking that I can relate, he tells me about all the friends he lost. I sit there and listen and offer my sympathies, keeping quiet about my own journey. I feel guilty, but why should I? I just want to scream at him that I wasn't 'lucky enough' for my disability to be the result of a one-off incident, I didn't have a traumatic injury – I know that having a traumatic injury isn't lucky compared to what happened to me but at the time that is what I felt like screaming at him – Instead, I had a slow six-year decline into this body, with a cancer journey that left me broken and stripped of my identity.

His tear streamed face suddenly reflects an explosion of red and blue, and we both silently turn as the fireworks begin.

Story 9: Forever the frustrated sportsman

When are you going to represent GB at the Paralympics?

This is a question I have frequently been asked. Like it's that simple to represent Great Britain (GB) just because I have a disability! Of course, it doesn't take years of dedication, discipline, or even an ounce of talent to play disability sport at that level, just a chair and a can-do attitude! (sarcasm clearly).

Before my disability, nobody ever asked me when I would be playing football for England – it was quite clear I did not possess the skill required (or any skill really). My wheelchair basketball game is at a similar standard to that of my old football game – nowhere near the standard of the elite athletes that get to represent their country but filled with enthusiasm! I am a recreational sportsman. I always have been, and I am okay with that. Elite wheelchair basketball athletes live the sport 24/7, they eat the right things, do the required gym work needed to be strong enough to compete against the best, and train multiple times a week. I am far too lazy to do any of that – and I've still got my music gigs to go to! But that doesn't mean that wheelchair basketball is any less important to me.

For me, participation in sport has always allowed me to get out of my head for a couple of hours, which means I can leave all my anxieties and pain worries behind. That's why wheelchair basketball is so important to me now; it lets me forget about the daily challenges of living with a disability and allows me to focus on something else. There have been times over the years that injury or health problems have meant I can't play, and I notice the effect that this has on my mental and physical health. I may be good at focusing on the negative aspects of my game and beating myself up over not being able to do something, but I am not completely angst ridden when I am playing. Wheelchair basketball has made me be okay with the new me. I will always have my anxieties, but participation in the sport has helped me to learn to live with the effects of nearly six years of cancer treatment and the years of treating the associated health problems that have followed.

Discussion

The stories presented are snapshots of key aspects of my identity destruction and reformation, within which hold insights to the complexity, rawness, and permanency of identity (re)construction after life altering illness and disability. In this section, I provide insight into the why and how of this autoethnography, as well as offering recommendations for those experiencing a loss of identity and those working in the field.

When I first started my PhD, one of my supervisors suggested I consider writing an autoethnography based on my own experiences of participating in wheelchair basketball, as my research focused on players' routes into and experiences of the sport. At the time, I was completely new to qualitative research and predominantly identified as a quantitative researcher (another identity shift!). The idea of writing my own story felt completely alien to me; it was too abstract, too subjective, too far removed from what I understood research to be. After mentioning it a few times and receiving the same dismissive response from me, my supervisor stopped bringing it up.

It wasn't until I read two powerful autoethnographies by Irish et al. [28] and Lowry et al. [29], that something shifted. Reading those autoethnographies brought me to tears as I saw pieces of my own story reflected back at me on the page. I wanted to be part of this. Something clicked and I opened my notebook and started jotting down fragments of my cancer journey and my route into wheelchair basketball. The process of writing my story was instantly cathartic. I found that the stories started to flow, with different memories of my journey and the emotions that accompanied them crashing back to me. Writing each story, I realised that I was reclaiming parts of my old life, accepting those parts that *were* me, and learning to embrace who I had become.

The first story I wrote was about my Mum passing away from secondary breast cancer during the Covid-19 pandemic. Although this story didn't make it into the final version of the autoethnography, I felt compelled to write it first. I needed to get it out of my system before I could fully focus on the rest of my journey. Writing about her death helped me process the loss and grief I felt and to shift my focus to the story I needed to tell; how I lost my identity during my cancer treatment, and how I slowly started (and still am) rediscovering it through wheelchair basketball. The last semi-lucid thing my Mum said to me before she died was, "*Why are you here? You should be at home studying.*" Those words stayed with me. They made me go home two days after she died to finish my master's and ultimately gave me the resolve to both pursue and complete my doctorate.

The stories I chose to include in this autoethnography represent key moments that shaped my identity. Starting with the initial fragments of stories jotted down in my notebook, I began fleshing out these key moments and turning them into something resembling the final versions included in this paper. This process was supported by my co-authors who either listened to my ideas or helped me shape the narrative. Once I had a first draft of the stories, I let my family read them and asked them to fill-in the gaps or correct me if my 'memories' were based off their experiences of my journey – something that was obviously the case when I was in a coma! Although my wife wasn't in my life during my cancer journey, I spoke to her a lot about the role of pain in my life. She knows what wheelchair basketball means to me, and how important it has been in aiding my acceptance of a disability identity. She therefore helped me in crafting these narratives. The creative process not only shaped the stories, but also further reshaped my understanding of identity.

I intentionally ended the narrative with two stories of being misidentified, first as a wounded veteran and then as an aspiring Paralympian. Coming to terms with my disability has been one of the hardest things I have ever done and there have been some very dark days where I wished I had not survived my amputation. I have worked extremely hard to accept my new way of living. I now take a lot of pride in my disability identity and feel like I have something meaningful to offer in the research area I have somehow stumbled into, having pivoted from cognitive neuroscience to disability sport for my PhD. Despite some acceptance, I still struggle with being mislabelled, stared at, or reduced to someone else's assumptions or punchline about what disability means.

Having never written in this style before, I was initially torn between producing an analytical or evocative autoethnography. However, after I began writing my stories I was inspired by the work of Ellis and Bochner [26] in choosing evocative autoethnography as I felt that I did not want to have to explain my experiences; nor is there a requirement for *anyone* going through a life altering illness to explain or justify them. Instead, I wanted the reader to care, feel, and empathise with my experiences, and reflect on their past or future actions interacting with someone from our community. As Ellis [23] suggests, I found that the process of writing the stories brought clarity and helped me become more present to my experiences. Through this process, storytelling became not only a method of inquiry, but a means of making sense of what I had been through and imagining who I might still become [31]. For years, I struggled to effectively articulate the psychological and emotional impact of years of cancer treatment,

trauma, and identity loss. But in writing this, I found an unexpected but powerful way of expressing what I had been through.

Sitting here now, having achieved what once felt impossible, I look back on my journey with immense pride. There was a time where I genuinely thought I would never work again. I had resigned myself to living in social housing, dependent on benefits, and disconnected from the life I once had. And yet, in the past nine years, I have completed an undergraduate degree, a master's, and a PhD, and have started working full-time as a research associate. The catalyst for all of this was wheelchair basketball. It wasn't just a sport, it gave me a sense of purpose, and most importantly, a community. Through wheelchair basketball, I rediscovered the joy of sport, I was able to feel a sense of freedom in a wheelchair I once felt bound by, and I started to build a new sense of self.

I am still a music lover. I go to gigs, obsess over albums, wear my favourite bands' t-shirts and head bang in my car. I'm still a brother, a son, a friend, an uncle. But I'm now also a husband, a wheelchair basketball coach, an advocate, a traveller, and looking ahead to new adventures and identities brought by my career and personal life. Another motivation for writing this autoethnography came from the many healthcare professionals who have been involved in my treatment. Over the years, many of them told me I should share my story with their colleagues as it offers a powerful example of how sport can transform the lives of individuals with disabilities. While I strongly believe that nobody should feel obligated to share their story, I am inspired by the words of Rogers [32] about the importance of sharing your voice:

I have almost invariably found that the very feeling which has seemed to me most private, most personal, and hence incomprehensible by others, has turned out to be an expression for which there is a resonance in many other people. It has led me to believe that what is most personal and unique in each one of us is probably the very element which would, if it were shared or expressed, speak most deeply to others (p. 26)

In sharing my story in this way, I hope that these reflections not only resonate with others but also contribute to a wider understanding of how identity can be reconstructed through the act of sharing our most personal truths.

Implications and recommendations

While I do not offer formal analysis of the stories included in this paper, consistent with an evocative autoethnographic approach, I do provide several reflections and recommendations for individuals experiencing life-changing illness or disability, as well as for those working within the healthcare profession.

For anyone going through a life-changing illness or disability

Although individuals experiencing life-changing illness or disability may face a disruption in their sense of identity, these periods of transition can also offer opportunities to (re)discover who they are and begin constructing a new disability identity. As the stories in this paper demonstrate, this process can be painful and messy, and it often involves taking small steps towards recovery rather than expecting to return immediately to a former sense of self.

Recovery from a life-changing illness or disability is rarely linear. Individuals may move forward, experience setbacks, and revisit earlier stages of adjustment. Although this lack of linearity can be frustrating, it is a normal part of the recovery process and recognising that progress does not follow a set timeline can support mental wellbeing.

Participation in sport or physical activity can support recovery by contributing to individuals' physical and mental wellbeing. Such activities may offer opportunities for social connection, provide distraction from pain and/or anxiety, and create genuine moments of joy. For those not interested in sport, other hobbies or creative activities can play a similar role in facilitating a sense of enjoyment, social connection, and escape during recovery.

Even small acts of agency, such as attending a new activity or visiting a local support group, can have substantial long-term impacts. Decisions that seem insignificant in the moment may contribute to increased confidence, expanded social networks, and the gradual (re)discovery of identity. Maintaining

communication with friends and family is similarly important, particularly during periods when individuals may be at risk of withdrawing or isolating themselves.

For healthcare professionals

Healthcare professionals do not need specialist expertise in sport to meaningfully support patients' engagement with physical activity. Simply having knowledge of local opportunities, NGB's, or organisations that facilitate inclusive participation can help signpost patients towards potentially transformative experiences.

A holistic approach to treating patients is essential. Individuals adjusting to a life-changing illness or disability often require support that extends beyond clinical management of their symptoms. Treating the whole person, rather than focusing solely on medical needs, may help patients to navigate the social, psychological, and identity-related aspects of their disability. Recognising the multi-faceted nature of disability can have a meaningful impact on an individuals' long-term physical and mental wellbeing.

Finally, the inclusion of lived experience in research, practice, and policy is crucial. People with direct experience of illness or disability bring unique forms of insight that can aid the direction of more inclusive, accessible, and equitable services for supporting those going through similar life-changing experiences. Their involvement should extend beyond mere tokenistic gestures. Individuals with lived experience should have opportunities to participate in spaces where decisions are made, ensuring that policy and practice reflect the realities of those most affected.

Final thoughts

I hope that my story, however personal, however painful the process of writing it has been, resonates with others. If even one person finds comfort, recognition, or understanding in these pages, then sharing my story will have been worth it.

"Today I woke up to a brand new me, I know I can't rewrite history, yesterday is gone, and I'm ready for what tomorrow brings" (Lyrics from 'Aftermath' by The Ghost Inside)

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