‘Cripping’ care in disability sport: An autoethnographic study of a highly impaired high-performance athlete.

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Abstract

In this article we combine the fields of critical disability studies and the sociology of sport to disrupt and extend current understandings of athlete welfare and care. A focus on athlete welfare is producing heightened awareness of the need for institutional, structural and personal support for athletes. Notions of ‘care’ are proliferating in sport discourse, with sport organisations routinely described as having a ‘duty of care’ towards athletes. In high performance disability sport, however, the provision and arrangement of care is often based on a view of the disabled athlete as high functioning, autonomous and independent. This perspective is further complicated when considering the provision of care for people with high support needs. Drawing on cripistemology, we argue that a politics of knowledge confirms a certain squeamishness around care practices and care knowledge in disability sport. One of us – a high performance, highly impaired athlete in Aotearoa New Zealand, offers an autoethnographic account of her experiences of training and competing, illustrating the embodied and intimate care needed for her continued engagement in high performance sporting practices. In keeping with wider calls in critical disability studies to bring the study of the body and therefore impairment back into disability discourse, we offer this personal narrative to ‘crip’ care knowledge, focusing on the materiality of bodies as they intersect with sport. Finally, we argue that sport scholars, practitioners and governing bodies must consider the embodied care politics of disabled athletes in order to deepen understandings of impairment, inequalities, and social inclusion.

High-performance disability sport; highly impaired athletes; care;
autoethnography; cripistemology

Introduction

Internationally, increased focus on athlete welfare is producing heightened awareness of the need for institutional, structural, and personal support for athletes. As such, notions of ‘care’ are proliferating in sport discourse, with sport organisations routinely described as having a ‘duty of care’ towards athletes. While care theory is gaining increasing momentum in the sport literature it remains an under-developed concept in the context of disability (cf. Fisher et al. 2019) and it is necessary to examine contexts that challenge the power relations on which traditional ‘caring’ relationships are built.

Elite, or high performance disability sport is considered a unique cultural formation. It is organised according to difference by a system of classification that orders and groups bodies according to severity of impairment) as a means of ensuring fairness and equity in competition (Berger 2009; DePauw 1997; Peers 2012. Research shows that involvement in disability sport provides positive opportunities for collective identity belonging and change-making, increased physical and mental self-empowerment, as well as health and fitness benefits which lead to a greater sense of control over lives and bodies (Berger 2009; DePauw 1997; Hargreaves 2000; Huang and Brittain, 2006). Disabled athletes, irrespective of classification, describe feeling strong and capable, resisting dominant ideologies about disability being weak, passive, inactive and dependent (Apelmo 2017; Berger 2009; Smith, Bundon and Best 2016).

In high performance disability sport, however, the provision and arrangement of care is often based on a view of the disabled athlete as high functioning in contexts that are outcome-driven, highly-pressured and built on often masculine ideals and expectations of athlete independence, resilience and autonomy (Townsend et al. 2018). Compounding these expectations are the proliferation of ‘supercrip’ narratives in sport which focus on the idea that it is possible to ‘fight’ disability – through determination and willpower – to overcome and achieve unlikely success in ways that are 'inspiring' to a non-disabled audience (Silva and Howe 2012; Schalk 2016). These perspectives promote the human-interest story (i.e., pity) over athletic achievement, which is belittled and trivialized (Peers, 2009). As such, high performance disability sport can reinforce the distinction between 'supercrip' bodies versus highly impaired[1] bodies (Apelmo 2017), and marginalise knowledge about the types and patterns of support required for highly impaired athletes to compete and perform at this level. This raises questions about the visibility and representation of disabled people in research, as well as critiquing the extent to which organisations and practitioners are well-placed to enact care and protect athlete welfare in high performance disability sport. Thus, the heightened awareness of the need for care is complicated by the lack of insight into the interpersonal relations and structural conditions that shape care practices in the context of disability sport.

Destabilising Ableist Knowledge and Practice

The article comes from a research project in which a central aim is to destabilise ableist[2] forms of knowledge and practice that continue within high performance disability sport (Howe 2009; Townsend et al. 2018). In this paper, our purpose is to shed light on the care practices associated with supporting athletes with low classifications, or those with high levels of impairment. In doing so, we conceptualise highly impaired athletes as 'bodies that need bodies'; that is, they have impairments that disable and are less able to function in everyday life without both structural and interpersonal support from others (Hargreaves

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[1] Throughout this article we use a variety of terms related to disabled athletes. Fundamentally, we foreground the constructed nature of disability (Kafer 2013; McRuer 2006) and it is our engagement with critical disability studies alongside the lived experience of the first author that drives our use of the term 'highly impaired'. For the first author, it is a personal preference; these words are synthesised from her experience and theory. In drawing on these discourses, we acknowledge the politics of language and the complex and shifting frames of reference we draw on to represent disability and impairment.

[2] Ableism, like sexism and racism, is discrimination on the basis of social status (Goodley 2017; Thomas 2004). Underpinning this discrimination is the belief system that "some people (and bodies) are "normal" and superior while other people (and bodies) are inferior" (Berger 2009, 41).

2000). In this sense, highly impaired athletes rely on extensive patterns and practices of support delivered and enacted by carers to help with the tasks of daily living and, by extension, participation in sport. These might be informal and intimate support structures like families and friends, or more formal arrangements of dependency, such as state-provided carers. We specifically draw on Thomas's (1999) 'social relational' definition of disability as a sensitising concept, allowing us to tease out and examine the gritty emotional, physical, messy lived experiences between (the lead author) and her family, carers and coaches (Smith and Perrier 2014). While physical *impairment effects* are unique to each disabled athlete, and directly impact on how that person engages in the world, often unnoticed are the psycho-emotional effects of disability (Thomas 1999). Importantly, the disabled body is more than just biological, it is also social and cultural, shaping "what one can do, and what one may become" (Smith and Perrier 2014, 102). In this sense, we use impairment effects to challenge the notion that "the body is destiny" (Linton 1998, 532) in high performance sport, as well as bringing knowledge about the impaired body – its material and embodied dimensions (Howe 2009) – into dialogue with the practices of high-performance disability sport (cf. Goodley 2017).

Researchers discuss how disability studies and the sociology of sport have developed in "relative isolation" (Moola and Norman 2012), as such the experiences of disabled athletes have not been brought to light (Peers 2009, 2012; Smith and Sparkes 2005). Responding to this call, the autoethnographic vignettes centre on the daily experiences of training and competition of a low classification swimmer aiming for Paralympic selection. Advancing the aims of critical disability theorists (e.g., Goodley 2017) and extending existing autoethnographic work in the sociology of disability sport (e.g., Peers 2012) our use of autoethnography is intended to open up multiple perspectives, unsettle meanings and spark critical conversations that give insight into how disabled people live. Critical disability studies is an intellectual project that aims to open up spaces for rethinking disability, dis/ableism and impairment and the ways that it is materialised in various institutions, including schools, workplaces, and indeed sport (Goodley, 2017). In this sense, we are influenced by Kafer (2013) as we seek to tease out and "contextualize, historically and politically, the meanings typically attributed to disability, thereby positioning "disability" as a set of practices and associations that can be critiqued, contested, and transformed" (9). Doing so allows for an exploration of care as lived and experienced, rethinking the conventions and assumptions of care theory through the intersection of impairment, disability and high-performance sport. We foreground a 'crip' position, designed to destabilise ableist forms of knowledge and to make something out of the messiness and inconsistencies of disability (Johnson and McRuer 2014; Kafer 2013).

Methodology

In this article we offer a personal, self-reflexive analytic autoethnography, written in the hope that readers can connect with the embodied experience of the lead author. Drawing from Anderson (2010), analytic autoethnography is not used "simply to document personal experience or to evoke emotional resonance with the reader" (386 – 387). Rather the aim is to use "empirical data to gain insight into some broader set of social phenomena than those provided by the data themselves (Anderson 2010, 386 – 387). In shaping this research, the lead author Amanda, discussed her experiences with her co-authors, who encouraged her to build on her experiences of training for the Paralympics to generate stories in a rich narrative form. This autoethnographic account, taken from her training journals, is an embodied and lived account of the processes of care for high performing, highly impaired athletes.

Given the critical lens required for this work, cripistemology drives the methodological approach (Johnson and McRuer 2014; Kafer 2013). Cripistemology draws from Haraway's (1988), 'situated knowledges' which is centred on the daily bodily experiences of being a crip, where "my future is written on my body" (Kafer 2013, 1). Importantly, cripistemology "emphasises the role that disabled subjectivity can play in both the undoing of traditionally assumed ways of knowing as well as the questioning of how we know disability" (Hickman and Serlin 2019, 135).

With cripistemology as our lens, we examine the 'realness' of having an impaired body in sport. What follows are four autoethnographic vignettes – using first person narrative and drawn from the lead author's journal – storying a 'day in the life' of a high performance, highly impaired athlete. These are considered analytically in relation to the existing gaps in disability sport literature to provide insight into high performance sport and the enactment of care. Drawing on personal experience, the first author offers her story, embracing her vulnerability as a purposeful critique of sociocultural practices; offering a powerful contribution to existing research (Anderson 2010; Holman et al. 2013).

Drawing inspiration from other disability sport scholars (e.g., Sparkes 2004; Peers 2012), we weave personal narrative with critical theory, articulating lived experience, which we then explore, explain and interrogate. This method allows reflections from [first author's] standpoint to be intertwined with relevant theory, in order to interrogate how care practices are understood and enacted in the context of disability sport. In recognising and articulating unstable, decentered crip positions, the methodological tools that are specific to critical disability studies - that is, the sensorial and experiential dimensions of what is to be disabled - can come to the fore (Hickman and Serlin 2019). The aim is that a "gift of living testimony" (Ellis and Bochner 2006, 431) will inspire the reader to care, to feel, to empathize, and to do something, to act, and to try to change the world (Ellis and Bochner 2006; Holman Jones 2011; Sparkes 2020). We recognise, however, that while this method is politically powerful, it may also reduce and universalise very different experiences of impairment and disablement. As such, there are multiple points for reflexivity to work throughout the research process. In particular it is important that we consider the ways in which 'who we are' both assist and hinder the process of constructing meaning (Smith and McGannon, 2017).

The first vignette "New Body New Life" locates the first author, describing how she acquired her impairment, negotiating her new body and (re)entry into sport through swimming and wheelchair rugby. The second vignette, "The Illusion of Time" documents the first author's experiences of crip time. The third vignette "Tokyo Looming" and fourth "Now or Never" provide some insight in the lead author's preparations as a member of the New Zealand Paralympic Development Squad, aiming for Tokyo 2021. Specifically, we emphasise the enormity of effort, care and support needed to get a highly impaired body to high-performance sport places. Throughout these vignettes, we highlight the felt experiences of this emotional and physical labour.

On writing and analysing

In writing and analysing these vignettes we move purposefully between the first author's reflexive insights (using 'I'), academic commentary (using 'we') and autoethnographic narrative (using 'I'). Central to the co-construction of these insights is the recursive and critical dialogue between the authorial team. Since the beginning of this research project in November 2019, we have regularly engaged in open and careful dialogue about the lack of research on the embodied experiences of highly impaired athletes. We, however, bring together our experiences as carers for close family members who are disabled, as well as scholarly interest in disability, inclusion and belonging across various social and cultural spaces, such as community participation, to sport, as well as health and physical education. As such, all authors were involved in the dialogue around ethics, care, ableism and sport, acting as critical friends to support and challenge the lead author in telling her story (cf. Smith and McGannon, 2017). While we emphasise that it is Amanda who leads this dialogue in order to 'crip' care knowledge and to destabilise ableist knowledge in disability sport, all of us are attuned to the various ways in which the politics of knowledge operates in sport research, hence, at all times we work towards challenging ableism in sport research.

New body, new life

How do I know disability? I was given a new body seven years ago. On the 7th March 2013, six days after the birth of our daughter Ziggy – a sister for three-year-old Lola – I dived off my surfboard, hit a sandbar and broke my neck. I suffered a 110% anterior dislocation, with C6 coming to rest in front of C7. My spinal cord didn't rip or tear, instead it stretched like a bungee.

The medical diagnosis is tetraplegia – I am paralysed, with 14% function from my chest down. All four of my limbs are affected. I have no bladder or bowel control, and no core so I cannot cough or sneeze or sit up. I have no temperature regulation, so I do not sweat or get goose bumps. My legs do not work and hardest of all my hands don't work.

A new life, and a new sporting life, began the moment I broke my neck. As part of my rehab, I got back in the water and spent two years assisted, learning to move my body and swim again. In the water was the first time I felt free – no wheelchair, and nobody touching me – what a gift. I started playing wheelchair rugby at the same time too and connected with a fabulous community that helped me negotiate the realities of my new body. I pushed hard, and both swimming and wheelchair rugby offered me high-performance opportunities. I chose swimming. In doing that I am breaking new ground.

There has never been an athlete with my level of impairment ever swim for New Zealand. But my inclusion comes at a cost; bodies like mine are not the norm in competitive swimming spaces. The spinal-cord injury that impairs me is a reminder that my body is always present. The way that others react to it constantly reinforces that I am different. As a disabled athlete I am in the perfect position to tell a story of 'bodies that need bodies' to participate in high-performance disability sport.

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Highly impaired people represent the most marginalised and excluded from so called normalcy, and as McRuer (2006) argues, "it is precisely those bodies that are best positioned to refuse 'mere toleration' and to call out the inadequacies of compulsory able-bodiedness" (31). Those who are most likely to engage in society and participate in sport are the most able of the disabled (Hammond et al. 2019), in other words, the 'supercrip'. The autonomous, self-sufficient "able disabled" can participate in sports clubs without any need for adjustment to existing structures and systems and coaches most value these athletes because they hyper-conform to standards of normalcy and ability (Hammond et al. 2019). These are the bodies most celebrated in high-performance disability sport. The mere act of being an impaired body (relatively powerless) in high-performance spaces with socially constructed 'normal' bodies (relatively powerful) facilitates an opportunity to tell a somewhat 'truer', reflexive and power-conscious story (Howe 2009). The narratives below offer a voice for those who are neither fully autonomous nor self-sufficient, that is highly impaired athletes whose stories have not yet been told and for whom care practices are essential for participation in sport.

The Illusion of Time

I open my eyes. I lie on my side. I hear my partner Gemma stir as she wakes behind me. She removes the bolster that keeps me in the same position overnight, and the pillow between my knees and rolls me on my back. My body protests, my muscles all tight, it shakes and spasms, sometimes my knees bounce to my chest. It is hard to breathe. When I am still, she lies in the crook of my arm for a moment. It's our only moment during the night when I know we touch. It is hard to connect when you can't feel. We are body to body, but I can only feel her on my shoulder. We rest and cuddle for a moment. She looks at the clock. It is 7.05. I've got to be at the pool to meet the support worker at 7.30. She jumps off the bed, and disconnects my night bag[3] *on the way to grabbing my togs and morning drugs.*

She pulls off the covers and begins my stretching regime. A short series of yoga postures that make sure that my hamstrings don't shorten over time, my ankles and achilles still have a range of motion required to sit flat on the footplate and so my hips don't atrophy. She removes my pyjama bottoms and begins to inch the togs up my body. She rolls me a couple of times to get them to my waist. She puts me into cross-legged position, and hauls my upper body forward so I am lying on my legs. The stretch feels lovely and I could stay here all day. It is over too fast as she removes my sleeping T-shirt. She pulls the togs up and over my boobs and shoulders. She puts the binder behind my back – I lie back on it – she does it up tight around my belly. I feel my breath strengthen, my blood pressure rising with the pressure from the tight elastic – I'm ready to go. She brings the wheelchair over to the edge of the bed while swinging my legs over the edge. I push myself up into sitting position, placing one hand on the seat of the wheelchair while she gets a handful of my togs. On three, I 'pop' into the chair. My left hip is down, she puts pressure on my

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[3] I have a suprapubic catheter – a hollow flexible tube that goes directly into my bladder to drain urine. It is inserted into the bladder through a cut in my belly just below the navel. Overnight the urine collects in a large bag or bottle.

right hip while pulling up on my left so that I am balanced. I choose a T-shirt from the chair and she slips it over my head.

Gemma's moving quickly around our house. I head into the bathroom to adjust my bed hair while she opens the van and puts my swim bag in. I roll to the table as she gathers my vitamins and gives them to me with a shot of lemon juice and hot water. I knock them back. I roll over to her and reach up for a hug, tell her to have a good day, and to cuddle the kids from me. When I'm training, I don't see them in the morning – every day I have to choose.

It is 7:22. I'm late. I hurry to the van. The hoist platform whirrs as I slowly get lifted into the car – I wish it went faster. I push forward into the drivers position and my chair locks into a metal bracket bolted to the floor. I lean forward and hold two buttons on dashboard that close the door and bring the backrest into place. The door shudders and closes slowly with a clunk. I clumsily search for the two Velcro straps hanging off the side of the backrest, wrapping them tightly around my belly to hold me upright while I drive. I click the seatbelt into place – finally ready to move I start the car and head off to the pool.

I meet my support worker Cherie in the car park at 7:28. She grabs my swim bag while I exit the car. While I put on my push mitts, she closes the van. We roll down to the pool and I zoom ahead down the steep path and into the door at the bottom to open it. The lifeguards greet us with a smile. We head to the far side of the pool to the hoist. We don't need to talk; the transfer is like a well-timed dance. In this moment, my support workers[4]

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[4] In the eight years since my injury my support workers have all been women aged between 30 and 50, with limited exposure to formal training. Support work is precarious, there is no job security and care agencies generally provide no training. On my team I have three support workers and my partner Gemma.

are an extension of my body; a necessary evil for me to live the kind of life I want to live. My interdependence is palpable.

Cherie puts the hoist seat in place ready for me to transfer. I park my wheelchair beside it and she removes my T-shirt and jewellery. She crouches down in front of me holding my chair firmly as I inch myself as far forward on my seat as possible, till my head rests on her shoulder for balance and support. She pushes my shoulders back so I can sit upright. I am perched on the edge of my seat, putting her feet between my feet, I lean all my weight forward so that my shoulder rests on her thigh – her hands are under my sit bones – on three we pivot to the hoist seat. I catch another swimmer's eye, they are staring, mouth slightly open – I know that they have never seen anyone like me get into a pool before. They quickly look away.

Cherie assists me to put on my cap, goggles and nose clip. I push the button on the hoist controller and raise into the air over the edge of the pool. She spins the chair around, and lifts my legs over the edge so I am facing the water and lowers it down. It is 7:45, I tell her to come back in an hour. I flop in face first. No one is touching me! There is no wheelchair. No one can tell how busted I am – in the water I am strong and free. I warm up my body, stretching out, doing slow double arm backstroke down the pool. Concentrating on my breath, feeling the spasm and noise in my body turning down. I swim about 10 lengths until I see my coach standing near the edge of the pool. I stop swimming – pulling myself up onto the edge. While my coach and I have a chat, I get him to tighten my goggles. He hands them back and gives me direction for the session. Cherie arrives back at 8.45. We repeat the process getting out of the pool and into my wheelchair. She dries my body and my hair, puts on my binder, and my T-shirt. And we roll out of the *pool. She pushes me up the steep hill and we head to the van. I open up and roll in and we both head home.*

I roll through my front door. Thankfully, it is not a toilet and shower day. I don't have the energy for another hour of hands-on care. I park next to the bed; she peels down my togs and we dress my upper body. While she is doing this, we chat about meal prep and my schedule for the day. I transfer to the bed, and she washes, dries and dresses my lower body. After, she helps me transfer back to the chair and hooks up my drainage bag that is hidden under my chair. I clean my teeth and tidy up my hair. 10am. Now time for breakfast.

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The narrative above highlights the mundane and monotonous nature of daily care, revealing a nuanced and critical consideration of time. It illustrates exactly how long things can take, the touch points, the barriers, the invasion of the personal self and other boundaries. From waking and getting dressed through to training at the pool, time is a commodity that rapidly diminishes through the everyday 'care' routines the first author requires. While 'clock time' is fundamental to the organisation of disability sport environments, these data are illustrative of the concept of 'crip time' (see Kafer 2013). Crip time is a relational phenomenon that only occurs because non-normative bodies are interacting with social worlds built on a particular version of normalcy (Kafer 2013). When oriented to thinking about time, able-bodied privilege can be understood as an "energy saving device". This is a useful tool for thinking about impairment effects: "we are saved from knowing what we are saved from doing" (Ahmed 2017, 182). Crip time requires a rethinking of understandings about what can and should happen in time, and recognising how “expectations of ‘how long things take’ are based on very particular minds and bodies” (Kafer 2013, 27).

Kafer (2013) highlights how the flexibility of crip time not only accommodates those who need more time but also challenges normative assumptions of pace and scheduling. Katzman, Kinsella and Polzer (2020) add to this understanding outlining how crip time reflects lived experience in bodies that are unpredictable and at times defiant, illuminating the “added layer of unpredictability that is a reality of many ‘crip’ lives” (522). In a crip world ‘the time that things take’ is dependent on many different factors that do not need consideration in an ‘abled body’. Crip bodies are impacted and mediated not only by body rhythms, but physical and social environments, people and technology – it is these factors that determine the pace of everyday life (Katzman, Kinsella and Polzer 2020). Indeed, as Kafer (2013) argues, “rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (Kafer 2013, 27).

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Tokyo Looming

This weekend’s competition is fast approaching. Gemma looks worried, “Do you think it would be worth going over the day before to check out the pool?” She’s right. I haven’t swum competitively for a year and I need to get some new qualifying times on the clock. The Paralympics is bubbling away in the back of my mind. Will I make the squad? My body has been misbehaving too; uncontrollable leg spasms have made driving interesting.

“Do you think we should do cares the night before the race so that your body isn’t too tired?” She’s looking at me intently, concern etched in her face. I decide that I’ll be okay

– that we'll have time – we can do cares the next morning. My support worker Julie arrives, and straps my feet to the chair – we are ready to go. Gemma gives me a squeeze, and wishes me good luck.

We arrive at the venue and find an accessible park. The lifeguards are lovely, and point me toward the competition pool. Julie helps me undress and put on my goggles, cap and nose clip, disconnects my leg bag and transfers me onto the hoist wet wheelchair. In the wet chair I awkwardly roll over to the hoist platform – at the last-minute she reminds me to remove my binder and I feel my blood pressure drop – I hope I can get into the pool fast – I feel like death. The lifeguard makes sure I am secure and slowly lowers the platform into the pool. As we are going down, I yell out to Julie, "there is some cash in my wallet, go grab yourself a coffee". I flop forward into the water – holding my breath, face down. My body spasms, legs tight and shaking, toes pointed. I roll onto my back as my body equalises and swim a couple of lengths to find my bearings – looking to find some markers or lines on the roof to guide my path for tomorrow's race.

I swim for about 40 minutes, confident that I will remember the space and then head to the hoist to get out of the pool – they lower it into the pool and I swing my butt around onto the seat, it moves slowly out of the water and then jams. I am stuck; my feet about half a metre out of the water, not yet on the edge where I can transfer to my wheelchair. I just sit there slumped forward in my togs, trying to prop my upper body, suspended above the water, I feel so exposed and vulnerable. The lifeguards are flustered but can't fix it. The only way to free myself is to I put my hands above my head and lean forward – crumpling into the pool. It is quite high and my hands and elbows hit the bottom (which is frightening given my history). Luckily there are some coaches who have worked with me before and who know how to lift me out manually. The coach pulls my upper body *back to the edge of the pool with my tog straps, preventing me from face planting into the pool. They grip underneath my armpits and squat lift my full weight, getting my butt onto the edge of the pool while trying not to scrape my back up the pool edge. Julie grabs my knees and spins me around. They reset their grip and count to three before lifting me into my chair. I am tired of being touched.*

An hour later than planned Julie gets me dressed, joking with me that if she'd known it was going to this long she would have told me to 'get stuffed'. I like her because she doesn't mother me. We load into the car and head back home. Our time together began at 7:30a.m. and we arrive home at 4.30p.m. Nine hours of paid support and 300 km for a 40-minute swim.

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This vignette illustrates two things. The first is the recognition that 'care' is a unique form of labour, not simply an economic transaction, but it is embedded in relationships and emotional connections (Duffy, Albelda and Hammonds, 2013; England 2005; Hochschild 1983; Walmsley 1993). The second point of interest in the narrative is the notion of 'cares' – an undocumented impairment effect that is largely absent from the disability sport literature, suggesting a certain squeamishness around care practices and care knowledge. The personal 'cares' described in the narrative refer to the assisted process of toileting and showering that highly impaired people require. Both of these processes cause a drop in my (the lead author's) blood pressure, and every morning I take a drug that raises my blood pressure to make the process a little less taxing. Sometimes the support workers have to lift my feet to prevent me from passing out. This process often takes between one to two hours to complete. It is fatiguing and at times unpredictable, and it has significant physiological effects on my body. For others, the practice of 'cares' is undertaken alone or with support depending on the individual’s level of impairment. A highly medicalised discourse embedded within rehabilitation, ‘cares’ is not an innate practice, rather, it is learned over time for both the support worker and the disabled person. Understandably, for athletes to perform their best, ‘cares’ need to be managed. Furthermore, for the highly impaired athlete the need for care extends beyond the bathroom and bedroom, as such care can be an intense form of physical and emotional labour for both parties. In particular, managing these care practices is psychologically taxing, where the psycho-emotional dimensions of impairment meld with physical restrictions of activity (Thomas, 1999). As demonstrated in the narrative, there is psychological fatigue of managing people who touch move and care for our bodies, and an ongoing emotional cost of being ‘out’ in public; where our “physical difference makes our bodies public property” (Morris 1997, 29). As such, the data further illustrate the politicised, visible and *felt* limits of the impaired body within high performance sport contexts.

Now or Never

It’s Sunday morning and we have chosen not to have a support worker because Gemma wants to come – she knows I am a bit nervous about racing again and wants to be there for me. At 7 a.m. we do stretches – I transfer onto the commode chair, shower and then she does cares.

Gemma puts me in my togs, with my clothes on top by 8:30 a.m. (nine hours before my race), because it would be too tiring and rushed to get changed at the pool. We drive to Hamilton and drop the kids off at friends and head to the pool at 4 p.m. for warmup.

During the week I emailed event coordinators to let them know that I am competing. They need to understand the limitations of my impairment and what might make it easier for them and me. With some discussion, they agreed to put me in lane one for all my races. I would get lifted in at the finish of the last race and move the short distance to my lane. I asked that they advise officials to wait until my body stopped spasming before they called the other competitors to the blocks. I just have to hope that this is what happens today.

I take a few deep breaths and get lifted into the pool for my warmup by Gemma and a lovely swimming coach. They joke about me having eaten too many pies. Once in the water my body calms down a wee bit – I feel so grateful to be away from the noise and the people – just doing my own thing – I try to find my rhythm and not to think about the hundreds of people watching.

My first race is 50m freestyle. When I propel away from the wall – every part of my body is yelling at me – high-grade pins and needles and intense spasm, one knee bounces up to my chest, my hands are tight fists and won't open. I can hardly breathe. The harder I try the worse it gets.

My body is a traitor.

When I finish, people are standing and clapping and cheering. The coach and Gemma lift me out of the pool and back into my wheelchair. Gemma dries me off, hooks up my leg bag and puts the tight elastic binder back around my belly. I feel my blood pressure rise. She then helps me put on a sweatshirt, a beanie and wraps my legs in a towel. There is an hour until my next race, and we have to make sure that I don't get cold. From behind she wraps her arms around my shoulders and gives me a squeeze; she can see I am struggling.

I sit by the side of the pool reflecting on my race – I feel angry at my body. A woman comes up to me and says "you're so inspirational" – that word makes me cringe, but I don't show it. Gemma stands behind them and rolling her eyes with a grin. I force a smile and say thank you. She then asks me, "why you do it when it must be so hard?" I reply: "I swim so that younger disabled people will see me and say to themselves, if she can do it, I can do it! I want it to be easier for them than it is for me! I want them to come knock 'the old bitch' off her perch". There has to be a reason – bigger than me.

The emotional responses of everybody else are exhausting. I know they mean well, but the fact that this happens every time I swim reinforces just how different I am. Bodies like mine are not the norm in competitive spaces.

My next race is 100 m freestyle. Gemma helps me roll quickly down the side of the pool as the last race finishes. As the other swimmers exit the pool, the coach and Gemma lift me out of my wheelchair, and I flop back into the pool. This race is better, my body is less annoyed, and I am pleased with my swim.

Luckily the pool has an accessible changing room with a height adjustable bed which means I don't have to drive home in wet togs. Gemma helps me transfer onto the high, hard, narrow plinth. Getting me changed in the stifling hot room takes 40 minutes. By the time I am dressed Gemma and I are both shattered. I stop her before we leave the room, and get her to bend down for a hug. Holding her tight I whisper "thank you".

Our eyes fill with tears. I am absolutely broken. Every part of my body is tired. A different kind of tired – there is sadness and darkness attached to it. Despite my independence, I am lifted, I am constantly touched, handled and hustled, and sometimes it hurts. There is a massive cost for Gemma too. She is my partner and she gets paid, but the work is *emotionally and physically heavy, hard and relentless. She takes care of all my material and physical needs while supporting me emotionally – creating a buffer between me and the social world. I really don't know if competition is worth it – for both of us.*

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The vignette above illustrates the weight of impairment effects in highly demanding, high performance environments. Specifically, we reveal the material, physical, emotional, moral and economic entanglements associated with (the first author's) impaired body and the care practices arising as a result. In centralising the experiences of an athlete whose impairment effects require intensive personal assistance; these data therefore unsettle normative notions of independence associated with disabled athletes as well as the forms of care evident in high performance sport generally. Dealing with impairment effects alone can be debilitating and demoralising. Yet, many disabled athletes have family, friends and formal support structures. The narrative exemplifies how the boundaries between the two can be blurred and the emotional toll this can take. Furthermore, the narrative illustrates how support work creates a space where family and market collide. Hochschild (1983) exposes the tensions embedded in work norms and expectations when the home becomes a site of work, and when private life becomes marketised. Family caregivers are in a particularly precarious position as their 'paid' work violates the social norms associated with caregiving which is generally viewed as an act of altruism (Stacey and Ayres 2019) blurring the lines between formal and informal labour (Stacey 2005).

Furthermore, (the first author's) lived realities reflect the 'interdependence' of disability living (Mitchell and Snyder 2001), producing an interesting and subtle tension that has implications for the arrangement of care practices and active support for disabled athletes. Mitchell and Snyder (2001) summarise how "the interdependency of disability living" is an important factor in achieving independence and autonomy (xii). For the able-bodied, independence is framed as being capable of doing things by oneself, whereas for the disabled is defined as the ability to choose and control the assistance needed (Morris 1995, 1997). Impairment itself does not necessarily create dependency and a lower quality of life – it is rather a lack of control over the physical help required which diminishes people's independence (Morris 1997). As detailed in the narratives, highly impaired athletes rely on extensive patterns and practices of care delivered by employed support workers, family and friends. The support that they receive is not just relational, as detailed in the sporting literature, but emotional and physical. Support workers are resources; 'vital and valuable human commodities' (Katzman, Kinsella and Polzer 2020) and the formal arrangements of dependency enable highly impaired athletes to participate, achieve and reach their goals in sport and in life.

Implications and Conclusions: 'Cripping' Care in Disability Sport

As athlete welfare continues to gain prominence in sports discourse, for disabled athletes, consideration of the lived realities of impairment - and the associated care practices and knowledge required to facilitate inclusion is needed. In this autoethnographic research we attempted to centralise the stories of the "absent subjects" (Morris 1995, 68) of disability sport; that is, highly impaired, high performance athletes – to raise awareness of the complex logistics of care underpinning their participation. The vignettes play a crucial role in raising critical questions around the formal support structures of high-performance sport. In presenting these stories, we shine a light on the under-theorised aspects of care as they intersect with disability; that of time, embodiment, labour and interdependency. Specifically, we highlight how impairment and the provision of care - its fleshy, messy realities - can have direct and unavoidable impacts on high performance disability sport. In highlighting the intersections between impairment, disability and high-performance sport, we 'crip' the conventions and assumptions of care. In doing so, we have illustrated how the role of care is difficult to reconcile in a high performance, ableist disability sport culture that celebrates independence and disassociation from notions of disability. In this context, many equate receiving care to dependency – incompatible with the ‘supercrip’ narratives that permeate disability sport. Furthermore, while care work is highly skilled – as highlighted in Hochschild’s (1983) research on emotional labour – in disability sport we know very little about the relational nature of care work from the perspective of disabled athletes and their support networks (Katzman, Kinsella and Polzer 2020). As highlighted in the narratives, emotional labour is undertaken by both parties in the caring relationship. It is multidimensional and requires the ability to think holistically, be prepared for complexity, to listen, communicate, reflect, and make appropriate judgements (Hochschild 1983).

In this sense, our aim is to highlight how insights generated by centralising the voice and experience of disabled athletes can challenge the ableism entrenched in practice in order to drive systemic change. Sporting organisations, from grassroots through to high-performance require a greater understanding about the levels of care required to have disabled athletes represented at all levels of the sporting pathway. We recognise that our interpretation is intertwined with our lived experiences and theoretical lens and we encourage others to engage with our narrative and analysis to extend it in new directions. Specifically, we hope that this paper can resonate with both researchers and practitioners in disability sport. While it has useful practical applications, primarily we want to invite greater representation of disabled voices; their thinking and theorising, to drive critical disability and sporting research. It is only when disabled voices and experiences are privileged that we can challenge not only the ‘taken for granted’ practices, but the ableist assumptions underpinning current sporting practice and the fabric of society.

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