

University of the Witwatersrand



Title of Research Report:

T(og)ether: Technological Attachment and Personal Detachment.

**An Ethnography of Athletes with Disabilities and Support Guides Running the New
York City Marathon 2019**

Masters Research Report

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**Research Report presented in partial fulfilment of the degree of MA by Coursework
and Research Report in Anthropology.**

I declare that this Research Report is my own, unaided work. It is being submitted for the degree of Masters by Coursework and Research Report in Anthropology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



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.....24..... day ofJuly..... 20.20.. at ..09:00.....



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A handwritten signature in black ink, appearing to read "Mucha Musemwa", is written over a horizontal line.

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Declaration of Investigator

To be completed in duplicate and one copy to be returned to Ms. Sarah Mfupa in the School of Social Sciences, Room 152, 1st Floor, Robert Sobukwe Block.

I fully understand the conditions under which I am authorised to carry out the abovementioned research and I guarantee to ensure compliance with these conditions. If any departure from the research procedure as approved, I undertake to resubmit the protocol to the committee.

Student Signature

Date

Abstract

Due to the multivalent nature of support and assistance, I aim to better understand what it means to provide “support” and “assistance”, especially for individuals with physical disabilities participating in mainstream sporting events. In this research report, I argue that the prevalence and implementation of (bio)technology’s assistive wearables and their predetermined algorithms dis-able such people from wanting to participate in such events. Such devices are not able to accommodate the complex human experiences, environmental engagement or support systems that are enabling factors for people to participate in a community activity. Within the sporting domain, one’s sense of self and physical self-perception is of vital importance if one wants to succeed. In this study, I examine how participation in one mainstream sporting event, the 2019 New York City Marathon, is challenged and reimaged by bodies defying the social norm of the sportsperson. Through personal narratives of individuals with and without physical disabilities who participated in the marathon, I critique technological forms of assistance. Through active participant observation, I have developed an alternative framework to rethink what it means to support and assist a particular human experience and embodied sense of being-in-the-world that cannot be reduced to predetermined quantifiable metrics. As supported by both the literature reviewed and my ethnography, an understanding and acknowledgement for the importance of embodied knowledge, physical self-perception, sensory engagement and the reciprocal nature of support and assistance from one physical body to another is fundamentally important to enable sports participation for all individuals. The intricacies of subjective experience and human connection should not be mediated by an impersonal attachment to an objectified device. In this research report, I demonstrate how human beings both physically and socially create a sense of support and togetherness, despite their (dis)ability to become technologically tethered.

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Keywords: assistance, biotechnology, community, disability, embodiment, phenomenology, senses, support

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Chapter 1: “pole-pole”

We are responsible for shaping and defining our lives, including to take adequate care of our physical selves by maintaining a healthy lifestyle and adhering to a fitness regime. Not all people can do this, however, for physical and mental health, social and economic reasons. Considering the progression and prevalence of (bio)technology as part of living in the 21st century (Yang, 2014), how are the complexities of the mind and body (Allen-Collinson et al., 2018), such as the interconnection between personal experience and physical engagements, being overlooked and replaced by a series of 0s and 1s? Our desires to engage with ourselves and our lived experiences are being replaced by the ability to translate our in-the-moment sensations into quantifiable data sets. Are humans able to adequately adjust to the physical demands of social progress? How will biotechnological change impact on the quality of human life and the ability to engage with lived experiences and sensations? (cf. Swartz and Watermeyer, 2008; Burkett et al., 2011)

In this thesis, I challenge the neoliberal agenda of producing the ideal citizen-subject who embodies the essence of physical capability: an able-bodied individual (Swartz and Watermeyer, 2008; Martschukat, 2019; cf. Maralack, 2016). Today, able-bodied athletes utilise wearable (bio)technological devices such as smartwatches and heart rate monitors to assist in their physical performance (Yang, 2014; Lupton, 2016). Through visual graphics, these devices analyse biological measures such as distance covered and active heart rate. This becomes an “overall” representation of physical endurance and exertion, or lack thereof. Because an able-bodied individual embodies the quintessential fit and healthy citizen-subject in neoliberal society, the algorithmic configurations promote an ableist agenda, through gatekeeping metrics of step-counting (Elman, 2018) and target heart rate zone relative to age, gender and assumed physical ability (Saw et al., 2016; Gabbett et al., 2017; Schneider et al., 2018). Individuals with [physical] disabilities are excluded; they are – by definition or by metric – neither fit nor healthy.

My focus is to explore what it means to be a body with a disability in the 21st century, within the social domain of mainstream sporting events. I focus on the 2019 New York City Marathon (NYCM), through which to better understand how individuals with disabilities navigate their physical selves in an ableist activity, and what is utilised to enhance their experiences of sports participation and so social inclusion.

“Assistive technologies” such as wheelchairs and prostheses, are intended to support individuals with physical disabilities to overcome challenges related to their particular impairment (cf. Swartz and Watermeyer, 2008; Burkett et al., 2011; Zeagler et al., 2018). But I also adopt a more generalised understanding of “assistive technology,” as any configuration of technology – digitised, modified or personified – that provides any mode of assistance in daily challenges, particularly physical performance.

I explain the multivalent nature of support and assistance, and explore why and how we should rethink what it means to provide support and assistance to individuals with [physical] disabilities (Hammer, 2015; cf. Darcy and Dowse, 2013; Bi et al., 2019). The various forms of “assistance” individuals with [physical] disabilities utilise are enabling technologies that allow them to participate as community members in social sporting events. These technologies should not highlight their limitations, but rather build their capability in ways not defined by algorithmic configurations and data sets (Zeagler et al., 2018). However, the prevalence and implementation of digitised “assistive technologies” prevent individuals from actively participating in social sporting events because of the devices’ ableist metric standards and predetermined algorithms.

I question how individuals with physical disabilities defy social norms around fitness and sporting culture, how they actively participate in mainstream sporting events, and how they challenge and redefine “assistive technologies.” What does it mean when we engage with our embodied experiences as physical selves as opposed to embodying the expectations of a digitised technological device?

Auto-ethnography

Pole-pole, if said without the right conviction and its correct Swahili accent, can infer an absurd understanding. However, if one is 5300 meters above sea level (MASL), the phrase implies the ability to listen to one’s body, garners a better self-representation, enhanced engagement with one’s environment, and the unrelenting support of Tanzanian guides and one’s family members who are performing the same activity.

On Thursday, 8 January 2015, my father, two older brothers and I attempted to summit Mount Kilimanjaro to raise awareness for the non-profit organisation, Operation Smile. The organisation’s goal is to provide surgery to children around the world who are born with cleft palates, to be able to smile for the first time. The stigma of cleft palates becomes erased, not only through medical assistance but also through the ability to give these children a reason to

smile. Climbing to the summit of the highest peak in Africa gave my oldest brother, Nick, the ability to realise his physical capabilities despite his involvement in a car accident at the age of nine, leaving him with a Traumatic Brain Injury (TBI) and right-sided hemiplegia. Our goal of climbing Mount Kilimanjaro was to celebrate our capabilities, despite physical constraints.

On the morning of our summit, after days of testing our physical, mental and emotional capacities to climb the mountain, we found ourselves insufficiently prepared. We had the necessary assistive equipment – waterproof hiking boots, walking poles and medication for altitude sickness (Acetazolamide); however, such assistive measures could not prevent the physical discomforts and struggles of mindset that Nick experienced for the first seven hours of our ascent. At 5300MASL, his inability to continue placing all of his efforts onto his left side to make up for the right proved to be so taxing that reluctantly, he decided to descend back to base camp. What got him to that point of near summiting was not his generic hiking boots, his two basic walking poles, and medication, although they did assist us throughout our journey. It was one of our two guides, Simon. At the start of our hiking journey, Simon built a relationship with Nick and was aware of his physical condition. He motivated Nick to push himself. He held Nick's right arm as we began the ascent, understanding that he needed assistance with the weakest part of his body. Simon became Nick's right-hand man, literally.

As my father, my middle brother and I were climbing, we often heard the Swahili phrase, “pole-pole,” loosely, “slowly, slowly.” Simon realised that Nick could push himself to the point where he was physically exhausted and mentally drained. The Swahili phrase and manner in which he said it allowed Nick and all of us to listen to our bodies, engage with the environment, and so further push ourselves and support others to do so while being cognisant of our varied abilities and capacities.

Reaching 5300MASL was an emotional moment. The decision to stop and question our capacity to finish was challenging but necessary. My father, mindful of Nick's physical condition, knowing what he was able to do, supported the decision that Nick descends with Simon. I knew this was not an easy decision. We revisited this during my interview with my father when I asked him what he was learning about Nick while training with him for the NYCM: “Nick is – it's very probable that Nick can run a marathon, 22 years after being told ... he will never *walk* again.”

On Mount Kilimanjaro, I knew that Nick could push himself, and questioned my father's support for Nick's descent. But I knew that it was made in Nick's best interest. Nick felt

confident with my father's agreement, smiled, and noted that were it not for Simon, he would never have made it to that point. It was difficult to watch Nick painstakingly climb back down with Simon tethered¹ to his right arm. My father, middle brother and I managed to summit to Gilman's Point (5756 MASL); none of us could get to Uhuru Peak (5895 MASL). We were not disappointed; rather we were proud to witness Nick's accomplishment and to be part of his journey.

Four years later, Nick was invited by a friend from his TBI counselling centre, Bevan, to run the NYCM 2019 with him. Bevan had heard about his Mount Kilimanjaro experience. The decision for Nick to run was not a difficult one, but it required careful consideration and active discussion. The decision was premised on the suggestion that my father would be Nick's support guide² – much like Simon had been – and so assist Nick in this new journey of defying physical abilities. Decisions on proper shoes, necessary equipment and effective medication came later, but again proved to be essential. The difference between this experience and that of Mount Kilimanjaro was that my father was not ready to help Nick back down but was happy to lift him higher, even if that meant tethering his left arm to Nick's right arm to ensure they crossed the finish line.

Nick is a motivational speaker. He talks about his accident and people's ability to overcome adversity and physical limitations, speaking of Mount Kilimanjaro as one of his proudest moments. He was the first individual to introduced me to the term "differently-abled;" he is a testament to what that term stands for and he is the drive behind this research.

The 2019 New York City Marathon was our next summit, and one we wished to do together, pole-pole.

^{1 1} The term "tether" has two definitions: first, it refers to restricting the movement of an animal by either tying it to a rope or chain; second, it refers to attaching someone to something by means of security. [<https://www.merriam-webster.com/dictionary/tether>] I refer to the term as attaching oneself to either (bio)technology by means of a wearable device restricting agency and the ability to fully engage with the human experience. Or to an individual by a mental or physical tether – as is the case for vision impaired individuals, enabling support and further guidance where necessary.

² Support Guides also referred to as "Guides" or "Support Runners" provide athletes with disabilities, ranging from vision, ambulatory, physical or intellectual impairment, verbal and physical cues that support the navigation of the runner. Support Guides are selected by the athlete with a disability. The support guide should also be familiar with the athlete with a disability. [<https://www.nyrr.org/tcsnymarathon/runners/guide-and-support-runners>]

Argument: The Peak of Human Ability

By engaging with various sporting bodies and my participant observation in the New York City Marathon, in this research report I argue that more consideration and acknowledgement is needed to better understand human capability. In the following, I emphasise the complexity of subjective embodied knowledge, self-perception, intersensory engagement and support systems. These factors cannot be mediated by technological advancements in assistive devices (cf. Burkett et al., 2011). I identify alternative forms of assistance for individuals with disabilities within a sporting context that progress notions of capability and acceptance of “different-abilities.” I do not question nor invalidate the usefulness of digitised (bio)technological devices. I do however recognise that technology has the potential to interfere with being human, delineating the body from the mind if we focus solely on its tether to social progress. I argue that realising the potential within these assistive features rests not on predetermined algorithms but rather on in-the-moment embodied sensations and the phenomenon of being human.

Chapter 2: Enabling the Detachment

The history of fitness and sporting culture is characterised by ableist ideologies, understanding and acknowledging that a sporting body is physically active, fit, and able-bodied. But what does it mean to be an active body in the 21st century? What are the mediating influences of (bio)technology, and how do we understand our subjective bodies through them? Accepting the prevalence and pervasiveness of (bio)technology in our everyday lives presents the need to further understand sensory experiences. The body has become an algorithmic configuration, overriding the nuances of human existence and experience.

The Age of ‘Me’

We currently live in an age of fitness, with our lives defined by (neo)liberal ideologies about the ideal social subject or participatory citizen (Martschukat 2019). To be fit is to both have and shape a body that suits the requirements of a (neo)liberal society. In outlining the history of fitness in America, Martschukat (2019) shows how wealthy white men are made into citizens by shaping themselves through ability, improvement and progress. Well into the 20th century, only wealthy (or wealthy enough) white men were able and had the right to live up to the core demands of liberal society and to pursue participatory citizenship. During the same time, women, African-Americans and individuals with disabilities were believed to embody deficiencies and to lack the ability and deprived of the right to self-govern. Essentially, ‘fitness’ is an “ableist subjectivation” (Martschukat, 2019: 159), which privileges those who are able to live up to the standards of (neo)liberal society. In this way, ‘fitness’ becomes a “dispositif” (Martschukat, 2019: 160; Foucault, 1980 [1977]) in both a liberal and ableist ascription, whereby our thoughts and actions are actively shaped by words, discourses, practices and institutions. Fitness exercises a level of power onto the body (Foucault, 1980 [1977]).

By the end of the 20th century, ‘ability’ had been reconceptualised as a form of “individualistic liberty” (Martschukat, 2019: 165) to reap the benefits of one’s effort. The 20th century, which Goodley (2017) terms the age of “neoliberal-ableism”, became synonymous with a culture of individualism (Martschukat, 2019: 165). ‘Fitness’ was thus realised as something to be continuously pursued. The individual physical body became the site for productivity, desirability and happiness. Neoliberalism’s ableist project sought to produce a particular kind of body and self, with the evaluation of every dimension of human life through systems of beliefs, practices and processes.

Given this normative ableist agenda, what happens to bodies which transgress the norm? (Butler, 2011). Today, we are bound by the ‘ability contract’ (Day, 2014; Martschukat, 2019: 169), which places the norms of fitness and ability at the centre of social recognition as participatory citizens. This contract ideologically delineates those who are able and those who are not. This is also exemplary of “bio[logical]citizenship,” which states that “human worth and fitness have been intertwined even more closely, and that the responsibilities of the citizen are literally embedded by fit and able citizens, who demonstrate awareness of the need for self-government and constant self-improvement” (Martschukat, 2019: 169; Rose and Novas, 2005). Is citizenship in modern neoliberal society then defined by one’s body and one’s active ability? How have we come to think of our bodies in relation to physical activity – especially considering the mediating forces of (bio)technological advancements in the 21st century?

The Age of Tech

The human body is both a lived experience and a vehicle for engaging with different practices and sites of knowledge (cf. the “body multiple”, Mol, 2002). How is it that we are being influenced by such technology and its accompanying digital data? Lupton (2016) contextualised this ontological entanglement by engaging with Mol’s (2002) analogy of eating an apple. Mol asked: does the apple, once ingested, become part of our body or does it remain a separate entity? Lupton (2016) considered this notion of “eating data” (Mol, 2002) by critically engaging with what happens once we ingest this technology and its data, questioning what influence this might have on our self-perception, further arguing that simply eating or pure enjoyment of the apple/data is contextual.

We live in an age of information that is mediated by and through (bio)technology. In order to better understand ourselves and our relationship to our bodies, we are urged to interpret ourselves as sites of quantifiable data and algorithmic configurations. Through this desire to know ourselves better, we have come to embody digital biotechnology (Lupton, 2016). Self-tracking through the active monitoring of physical activity, such as through Fitbits and smartwatches, is increasingly part of the everyday life of many individuals, making them “algorithmic bod(ies)” (Yang, 2014: 82). Biotechnology has not only made our bodies artificial but also offers us opportunities to escape the human condition (cf. Arendt, 1958), allowing us to transcend our bodily limitations and its uncertainties; however, as Arendt (1958) feared, this makes us lose that which actually makes us human. As Burkett and colleagues note,

“technology is sometimes seen to dominate its users by creating dependency and distorting human relations” (2011: 645).

Contexts such as conforming to ideals of “healthism” (Lupton, 2014: 709) allows self-monitoring to influence individuals’ perceptions of their physical self. Lupton (2014) reports that according to a 2013 market research study, one in every 10 Americans had digital fitness trackers but after six months of use, half had relinquished using the device and one in three simply gave up on the device as it influenced how they viewed their body in relation to their physical activity. Their negative self-perceptions were a consequence of their activity being rendered into biodata and its algorithmic configuration. The biodata which these users produced had commercial “biovalue” (Lupton, 2017: 4) for life and health insurance companies. These companies incentivised their clients not only into self-tracking but also to willingly share their data by implementing a rewards system – such as lowering insurance premiums. The data generated was sold on to and exploited by different commercial, managerial, governmental and research agencies. Lupton (2017) argues that this has become increasingly normalised in the Global North, as neoliberalism tends to reward and privilege those who conform to ideals of productivity, self-governing and self-responsibility (cf. Martschukat, 2019). This is relevant also in the Global South, in so far as such incentivisation has been taken up by health insurance companies (for instance, Discovery in South Africa, which will be further discussed in my ethnography) despite that the majority population is poor and many, including individuals with disabilities, are marginalised and stigmatised. Lupton questions the effect of self-tracking on such people given that “repositories of data about people’s ... health conditions can be used to target them for social shaming” (2017: 4). Ruckenstein and Schüll (2017) further questioned how ‘health’ is defined, in relation to different data processes, further problematising the position of marginalised groups and how the effect of data technologies on them (cf. Lupton, 2017). Their vulnerability is evident in how “individual self-tracking data can have social, and political potential when it is pooled to identify health inequalities [and] collective environmental exposure to disparities in quality of life” (Ruckenstein and Schüll, 2017: 272). Self-tracking can promote health and well-being, but it also contributes to marginalisation.

Marginalisation is realised through social discourses around health, fitness and disability which create “body panics” that are assumed to be resolved through “body work,” including through the use of self-tracking devices (Sanders, 2017: 48-49). These devices place users under surveillance and constant (self-)policing, so that digital self-tracking and monitoring are no

longer acts of doing, but a “dispositif” on living (cf. Foucault, 1980 [1977]; Martschukat, 2019). Sanders (2017) has suggested that despite imposed societal norms of health and fitness, by eliminating potential stress of “body panic,” we could explore an embodied sense of self-transformation. As Lupton (2014) has argued, subjective understandings of the body as both experienced and inhabited are influenced by our self-monitoring practices. We can either feel empowered by both engaging with and analysing our data to improve our physical performance, bodily knowledge and sense of self, or we can feel discouraged by the sociocultural ideal and standards of ‘fitness,’ completely overwhelmed by our data.

Furthermore, Smith and Vonthehoff found that digital “unbodied” data from devices can displace embodied knowledge and bodily intuition (2017: 19). Similarly, Rapp and Tirabeni (2018) in exploring different conceptions of self-tracking devices or “Personal Informatic” tools (PI), illustrated that comprehensive monitoring of an athlete’s performance is essential to guide training, understanding the athlete’s response to training and knowing what they want to achieve – in relation to the physical demands of a particular sport. Developments in digital wearable and monitoring tools have allowed for improved understanding of an athlete’s physiological responses to physical activities. Such wearables are time efficient for response and non-invasive (see also heart rate monitors in Schneider et al., 2018). According to Rapp and Tirabeni’s (2018), elite athletes – out of convenience – tracked and monitored their performance trends, but they also believed that their bodily sensations exceed the limitations of the tools. Amateur athletes, in contrast, tracked out of curiosity and regarded the data as a supplementary source of information. As much as these tools allowed athletes to make sense of their bodies, there were also times when subjective knowledge, bodily sensation and internal knowledge was subordinated to the device, as one elite athlete noted, “it becomes a bad thing because you become truly a machine. And it’s a bad thing because sport, in my opinion, must be a little romantic, must value sensations too” (Rapp and Tirabeni, 2018: 13). In line with this, Saw and colleagues (2016), Gabbett and colleagues (2017) and Schneider and colleagues (2018) all note that certain devices, such as heart rate monitors, are unable to take into consideration other influencing factors such as the environment, lifestyle and subjective measures of well-being which may impact on an athlete’s overall performance. A more holistic assessment – which is essential for individualised analysis – combines subjective measures of an athlete’s physical and psychological well-being with objective measures such as workload. Rapp and Tirabeni consider how both the objective and subjective modalities of the device are interactive, so allowing us to reconsider the device as a prosthesis, “extending the body

capabilities instead of substituting them” (2018: 23). This embodied approach to data would entail “a prosthetic of feeling that can help us sense our bodies or the world around us” (Nafus and Neff, 2016: 75; Ruckenstein and Schüll, 2017: 268).

However, these self-monitoring devices are still incapable of adapting to the nuances of its users’ everyday lives, creating “a disconnect between how someone ‘should’ feel and how they actually feel” (Toner, 2018: 76): they do not provide insight into a lived body as a body of experience of an individual, including of sensation (Merleau-Ponty, 1962; cf. Mol, 2002). “Biomonitoring” anaesthetises human experience and removes the embodied experience from the body itself (Toner, 2018: 75). The device reduces and inadequately reflects the richness of embodied phenomenological experiences, while reinforcing social ideals and norms of body capability, including in this context what constitutes good athletic performance. Toner suggested that we listen to our bodies, engage with our personal experience of physical movement and the challenges that come with it so that “we can acquire bodily knowledge ... to develop a deeper understanding of their movement and how this knowledge can be used to guide practice” (2018: 78). Hockey and Allen-Collinson, in their autoethnographic account of their experiences as serious, committed athletes, similarly expressed how “the body is at times brought actively and forcibly to the forefront of consciousness in training and racing, during experiences of intense embodiment” (2015: 2). Allen-Collinson and colleagues (2018) have illustrated this in their study of high-altitude mountaineering in Nepal and the ‘endurance work’ of local guides (Sherpas). Considering the severity of the physical task and the mental stamina needed to maintain endurance despite exhaustion is “not so much ‘mind over matter’, they argue, but rather mind and [body] matter as fundamentally interlinked at the task at hand” (2018: 1333). Hockey and Allen-Collinson (2015) engage in long-distance running and noted through an account of stoicism, the ways in which executing endurance in the face of adversity becomes embodied in a ‘sporting mind’, further considering the interconnectedness of mind and body in the lived experience of the lived body (cf. Allen-Collinson et al., 2018). Bi and colleagues (2019) further noted how an athlete’s motivation to participate in endurance running can either be extrinsic – the honour and reward, the atmosphere or the audience, or intrinsic – running for the enjoyment of it or a sense of well-being. The sense of well-being for the athlete includes: emotional (affect and its relationship with running performance), physiological (sensory engagement with their environment) and/or cognitive (coping strategies for endurance running). Cognitive well-being can be further characterised as being either associative, with a focus on the internal state of the sensed body in order to respond to the body’s needs, or

dissociative, with a focus on external events, such as maths equations, to reduce pain and boredom. Bi and colleagues (2019) argue that these components interact to form the totality and subjectivity of the running experience. Hockey and Allen-Collinson explained how the physiological experience of endurance running influences one's habitual "endurance consciousness," with "ongoing [internal] sensory monitoring" and the fluctuation of the "mind's bodily focus" (2015: 5-6; "cognitive" in Bi et al., 2019), which in turn validates their/one's athletic identity ("emotional" in Bi et al., 2019). They consider endurance running a "sensory assemblage," whereby the body is a site of immediate lived sensations and "learning endurance is a process in which the individual runner internally experiences a particular set of sensations, interprets those sensations so as to make them meaningful and then learns to deal with them" (Hockey and Allen-Collinson, 2015: 8). One example would be fatigue as a feeling that becomes familiar and normalised as a response, learnt through "bodily memory" and comprised of both perception and experience (Hockey and Allen-Collinson, 2015: 10). Developing somatic awareness and knowledge is based on experience; athletes come to learn under what conditions they perform most effectively, and not; they also develop the skill of sensing their immediate environment and acknowledge the importance of hydration, food intake and body physiology (heart rate, bodily pains etc). However, more consideration is needed for how one can come to effectively learn about their body if there is constant promotion of what an effective individual body should be.

Dis/ability Theory

When does experience become disconnected from expectation? How is the division between disability and able-bodiedness realised and promoted by technological advancements? Why is disability presented as a binary opposite of ability? Will there ever be an opportunity for freedom of movement along a continuum of different abilities? Toner suggests that device developers be mindful of device users and urges that "fitness tracking technology (should) avoid the promotion of normative behaviours and instead, allow(ing) users to identify what they see as worth promoting in terms of their own health" (2018: 80). Developers should also consider the accessibility and usability of their devices by enhancing their capabilities as assistive technologies. Zeagler and colleagues (2018) included as considerations: body motion, tangible/tactile/haptic feedback and social acceptability. In consideration for individuals with [physical] disabilities, developers should design devices that are universally acceptable by diversifying the range of possible users, considering the potential of these devices to become game-changers in the realms of health, fitness and sport. Zeagler and colleagues (2018) also

argue that developers should be sensitive to and aware of the diversity of needs among individuals, and that not all might wish to draw attention to the need for assistive technology, nor to make disability the focus of social and/or sporting attention.

Disability was the central focus in Fitbit's³ 2014 commercial, "Find Your Fit," which included individuals engaging in unconventional and untraditional forms of exercise, such as a father pushing his wheelchair-bound son. Elman noted that such imagery linked unique ways of engaging in physical activity to the Fitbit user, promising individuals greater control over their bodies through a "playful sense of surveillance" (2018: 3761). However, Elman (2018) also identified the disconnect between visible disability in the commercial and the technological capabilities of the device, which could inadequately and inaccurately capture the movement of the wheelchair, given that it was designed to step count (as opposed to wheel rotations, for instance). Fitbit profits from able-bodiedness, implying that "able-bodiedness is the natural and desirable form of embodiment or way of life" (Elman, 2018: 3761).

Social discourses and "body panic" (Sanders, 2017) around disability shape not only the impact of advertising but also social norms of able-bodiedness as associated with concepts of 'health' and 'fitness'. Such 'bodily ideals', according to Swartz and Watermeyer, amount to "the neo-liberal pecking order of capital accumulation and the economy of power" (2008: 188). This culture ensures the social practice of measuring oneself in relation to others. The Fitbit commercial reinforces the association of athleticism and able bodies, and conversely excludes disabled bodies; a disabled body is not a desirable body without the assistance of some form of (bio)technology. Elman (2018) concluded that the commercial promoted a device that remained inaccessible to the very bodies used to advertise it, highlighting the need for developers of the device to destabilise normative ideals that equate able-bodiedness with mobility, freedom and fitness (cf. Matschukat, 2019).

Inaccessibility opens up questions of how cultural membership and social organisation inform how we understand 'disability'. In elaborating on socially constructed ideals, Anastasiou and Kauffman (2013) distinguish the medical model of 'disability' whereby an individual is either functionally or physically limited ('impaired') from the social model of 'disability', referring

³ Fitbit (founded in 2007 in USA [<https://www.fitbit.com/us/home>]) [and Garmin (founded in 1989 in USA) [<https://connect.garmin.com/>]] devices are wireless enabling technologies such as smartwatches and heart rate monitors that actively measure the user's physical performance and personal metric, such as steps covered and average heart rate. The data collected is then allowed to be synched onto the user's mobile device and stored on the device's appropriate mobile application. The data can also be shared with either insurance companies (for health and wellness incentives) or other device users (within the same sporting community and to create a friendly sense of competition).

to the social exclusion of these individuals from mainstream society; they noted that individuals with [physical] disabilities considered the social exclusion, discrimination and hostility they experienced was disproportionately greater than their impairment. Constructed from such ableist attitudes, the social values of disability are judgemental. Furthermore, the social systems and structures that privilege able-bodiedness provide the context in which an [physical] impairment becomes a ‘disability’. Lindemann and colleagues (2017) note that in the medical model, ‘disability’ is understood as something in need of fixing through surgery, physiotherapy, prosthetics or orthotics, or now, possible digital (bio)technology; the social model challenges this by implying that disability may be ‘fixable’ if we better understand the social factors that impact on an individual with a [physical] disability.

Lindemann and colleagues (2017) argued that the social model aims to elucidate and improve the lives of individuals with [physical] disabilities through organisational movements and policy implementation. This is what Dirth and Branscombe (2019), as well as Howe (2011), have referred to as “disability in action.” To create such opportunities for necessary change, Dirth and Branscombe (2019) conducted two online surveys in 2018. The first was to determine the impact of socio-cultural beliefs on a group of individuals with disabilities, and their perceptions of exclusion and discrimination as illegitimate and unjust. They found that the stronger one’s social identification with other individuals with disabilities, the more likely they were to view exclusion and discrimination as illegitimate and unjust. The second survey aimed to understand their participants’ beliefs on whether the disability/ability divide could be transcended. Dirth and Branscombe consider the role of disability support groups and communities is to “co-construct what it means to be part of the disability category” (2019: 20) through discourse and organisational participation; inevitably, this will shape how individuals understand and think about [their] disability.

As previously noted, the social model of disability focuses on the social privileging of ableist norms and the importance of resisting this. In the sports domain (Zeagler et al., 2018; Elman, 2018), the aim is to create an enabling environment for individuals with [physical] disabilities (Dirth and Branscombe, 2019), and “on addressing an individual’s specific access needs” (Darcy et al., 2017: 20; see also “impairment effects” in Darcy and Dowes, 2013). Darcy and colleagues (2017) conducted a study with disability organisations in Australia to understand the constraints individuals with [physical] disabilities experience when participating in sports, which they define as a leisure activity. They identified four “leisure constraints,” that is, “factors that limit the formation of leisure preferences or inhibit participation” (Darcy et al.,

2017: 22; Jackson, 1991). These are: (i) “community/organisational support” focuses on the availability of and inclusion in sports programmes, (ii) accessibility and availability of either adaptive or specialist equipment, (iii) “interpersonal” constraints that are “shaped by a PwD’s [People with Disabilities] perception of the environment and disability consideration” (Darcy et al., 2017: 28), considering how an individual with autism, for instance, might find overcrowding to be a sensory overload and (iv) “intrapersonal” constraints due to the lack of companions with an understanding that some individuals “find the social nature of sporting activities problematic, especially since they do not have others with whom they can share their experience” (Darcy et al., 2017: 28; Darcy and Dowse, 2013). Darcy and Dowse especially note how “supportive and flexible organisations with personnel – including support people, volunteers and coaches – with an awareness of disability issues and knowledge of appropriate ways to support an individual with [a] [intellectual] disability [is] a key area of need” (2013: 401). Darcy and colleagues (2017) argue that the higher one’s support needs – ranging from independent to very high – the greater the experience of constraints. They also insist the predominant constraint is not the individual’s disability but the lack of an “enabling policy of attendant support in a sporting environment” (Darcy et al., 2017: 36). An individual’s disability and support needs (Abdullah et al., 2008; Darcy and Dowes, 2013) should be better acknowledged; and technology may not be effective in this regard. Rather, “a better understanding of how these constraint factors socially construct the sports environment for PwD may then lead to transformative solutions that impact participation at the community level to enhance sport development pathways in mainstream and disability sport” (Darcy et al., 2017: 37).

In 2016, the organisers of the Two Oceans Marathon⁴ and Comrades Marathon⁵, both South African long-distance running events, declined entry to two wheelchair participants, claiming the events to be too physically demanding for them and that there would be issues of integration. In reviewing and commenting on “the constitutional right for differently-abled athletes to be permitted to participate in any event,” Maralack (2016: 59) considered the dilemma of the race organisers’ understanding of their responsibility to comply with various health, safety and environmental rules, regulations and procedures, and the tension between these and the importance of working within a “human rights culture” (2016: 59). He noted how

⁴ The Two Oceans Marathon is an annual marathon (56km) event that is run in Cape Town in April. It is often referred to as “the most beautiful marathon”. [<https://www.twooceansmarathon.org.za/>]

⁵ The Comrades Marathon is an annual ultramarathon (89km) event and is run in the Kwa-Zulu Natal province of South Africa in May/June. [<https://www.comrades.com/>]

international organisations such as the Road Runners Club of America (RRCA) facilitate discussions around enabling sports participation for individuals with [physical] disabilities, with special considerations for health and safety that are not premised on generalisations or stereotypes surrounding disability. While he proposed that adequate guidelines be created through active discussions, such policies intended for inclusion “threaten the order of established categories and remove the comfort of clear [abled vs. disabled] boundaries” (Swartz and Watermeyer, 2008: 188), thus impinging upon notions of “fair play” (see also Burkett et al., 2011). The RRCA emphasises that it is the responsibility of the individual/athlete with a [physical] disability to request an accommodation for participation and the responsibility of the race organisers to ensure that such participation is an option and that reasonable consideration for implementing adjustments can be made. In the local context, the South African National Sport and Recreation Plan (NSRP) emphasises inclusion, but again, accommodation guidelines and implementation are the responsibilities of the race organisers, who need to carefully consider appropriate safety measures (traffic, experienced volunteers and medical services) in line with the South African Safety at Sport and Recreational Events Act of 2009 (SASREA)⁶. Although some instances of participation, including the route of the course and adequate spatial accommodation for wheelchair users, might be limiting for athletes with [physical] disabilities, stakeholders such as the Western Province Sports Association for Physically Disabled (WPSAPD) need to ensure that risk assessment is “based on sufficient knowledge in the area of disability or has consulted with the appropriate disability organisation” (Maralack, 2016: 60; Darcy and Dowes, 2013). Maralack (2016) maintained that as athletes, individuals with [physical] disabilities should endure the same physical effort, risk and challenges as other athletes and the option to participate should, therefore, be available (see also Abdullah et al., 2008); not dissimilar from the case of Oscar Pistorius in the 2008 Olympic Games in Beijing (cf Swartz and Watermeyer, 2008; Burkett et al., 2011).

Kissow and Singhammer (2012) conducted a study in Denmark with individuals with a physical disability who participated in some form of physical activity, and similarly argued for their greater freedom of participation in social sporting events. They suggest that participation be determined for all individuals without attention to normalised social standards. Kissow and Singhammer (2012) found that physical activities need to be made more adaptive and accessible, noting that individuals with physical disabilities feel empowered through body competence and social competence. Abdullah and colleagues (2008) considered the role of the

⁶ https://www.gov.za/sites/default/files/gcis_document/201409/safetyatsports.pdf

coach for these individuals, with coaching valuing both the importance of training and an understanding of disability as unique, the individuals need of acceptance, and the opportunity participation gives them to gain a greater sense of self and performance satisfaction. They argued that the coaches of individuals with physical or neurological impairments design training programmes that appropriately accommodate the needs of the athlete, such as achieving greater motor control and greater flexibility (Abdullah et al., 2008: 54). The coach is knowledgeable about the rules of the sport, aware of the necessary equipment, and flexible in training, reinforcing the strengths rather than weaknesses of athletes. Saw and colleagues (2016; see also Gabbett et al. 2017) noted that a holistic approach will better reflect an athlete's response to training and can help coaches design training programmes specific to individual athletes. Such programmes might include ways of guiding individuals with vision impairment (for example, using tethers) or improving the mechanics of a wheelchair, acknowledging that "satisfaction with performance appears to be of vital concern to athletes with physical disabilities" (Abdullah et al., 2008: 56).

Shapiro and Martin (2010) and Scarpa and Palumbo (2017) both noted benefits in participating in adaptive sports for individuals with [physical] disabilities as a basis to identity formation and to gain confidence. However, Shapiro and Martin (2010) note that "reduced participation levels may be due to a number of barriers such as ... organizational policies, discrimination and social attitudes" (2010: 296). Both research teams noted how cognitive processes and social experience influenced individuals' understandings of their body-self, acceptance of their disability, and overall self-esteem. Scarpa and Palumbo (2017) studied the perceptions of individuals with either acquired or congenital disabilities and found that "one's identity perception, including bodily considerations, is shaped by social recognition that happens in exchange with 'others' ... a person with a congenital disability undergoes, starting from birth, a series of stigmatising social influences by significant others" (2017: 10). Acknowledging one's physical self-perception is not only a matter of gradual adjustment and acceptance of one's disability over time; it is also to know that such perceptual development happens in a social context (Dirth and Branscombe, 2019). Motivation to participate in physical activity by individuals with [physical] disabilities were premised on their perceptions of competence, especially in relation to others. Shapiro and Martin (2010) noted psychological factors results in self-exclusion when participants believed themselves to have more body fat and less endurance than able-bodied counterparts. They suggested that participation in organised adapted sporting activities might help these individuals "realize not only that the prevailing

stereotypes surrounding disability are inaccurate representations of their potentials but that participation in adapted sports offers an opportunity to redefine their physical capabilities” (2010: 303). Darcy and Dowes further support the intersection of social ideals and the disincentive to participate in sporting events:

There is likely to be a complex inter-relationship between these constraints, where the physical and psychosocial effects of impairment intersect with the social conditions created within a society where disability and the concomitant issues of access and support are poorly understood and resourced (2013:402).

Scarpa and Palumbo (2017) also maintained that opportunities for participation through adapted sports improved individuals’ mental representation of their body-selves.

Sport is an embodied practice. The body-self is essential in sport, and impaired bodies are marginalised and stigmatised (cf. Ruckenstein and Schüll, 2017; Lupton, 2017). As previously argued, the bodies of athletes with disabilities are continuously judged against able-bodied athletes, normalising the standards of participation and performance in mainstream sporting events and competition to an ableist configuration. Fisette (2015) noted the importance of gaining a deeper understanding of an individual’s body-self and performance identity. She presents this through an autoethnographic account of her journey of re-embodiment, from identifying as an able-bodied self to her experience of an unexpected impairment. Fisette (2015) challenged her previous performance identity and openly expressed her difficulty identifying as an impaired body-self because socially constructed ideologies of ableism were deeply ingrained in her self-perception formulation and acceptance. In her autoethnography, she details how she came to accept her new body-self, from being told she had herniated discs in 2001 to her success in completing a half-marathon in 2009. In her account of her journey of self-(re)discovery, she critically engages with the social norms of athletic identity as able-bodied. She narrates her own difficulties in defying these norms by completing the marathon, and moments of self-doubt as she questions her capability of performance. However, she recalls Theresa, her running partner, asking her rhetorically: “If you don’t view yourself as a runner, then who is a runner?” (Fisette, 2015: 80). Fisette began to accept her new body-self, noting that she did not know where she ‘fit’ “within socially constructed labels ... [but] what I do know is that regardless of the bodily problems I experience, I am on a quest to discover what my body can physically endure despite my limitations” (2015: 85). She concludes by reiterating that we are all bodies who experience bodily problems and that it is up to individuals, not

society, to determine our own body narrative as “the body-self exposes how each individual has their own story that influences their embodiment and, in this instance, performing identity” (2015: 86). Lived experience thus blurs the “internal-external distinction” (“mind-body nexus” in Hockey and Allen-Collinson, 2015: 18), allowing the individual/athlete to develop a mutually influencing performing mind and performing body, which validates their athletic/performing identity.

Hockey and Allen-Collinson consider endurance running is an embodied experience that is consistently learnt and relearnt through training and an understanding of one’s “athletic consciousness and of general being-in-the-world” (2015: 18; Allen-Collinson et al., 2018). In line with this phenomenological understanding, Howe (2011) argued for a reorientation of our approach towards athletic bodies as able bodies, suggesting instead that we view an athlete’s body as a sensory body experienced and engaged with being-in-the-world, and that “an impaired running body can act as a stimulus to our senses and help shape our interpretation of the world” (2011: 276). Howe was an athlete who participated in the 1996 Paralympic Games representing Canada. Through reflexive narration and engagement with his fieldnotes about that experience, he allows the reader to understand the importance of one’s sense of being-in-the-world and its entanglement with the sensory body. Through his standpoint epistemology – which “places the voice of the underrepresented at the centre of research” (Howe, 2011: 286) – he presents a phenomenological account that engages with “the sensuousness of the sporting body” (287). Howe (2011) critically engaged with Foucault’s “disciplined body” (1980 [1977]) and Bourdieu’s theory of “habitus” (1977), and with Merleau-Ponty’s notion of “being” (1962), insinuating the subjectivity of one’s environments into one’s sense of agency. Howe understood his/the body to be “co-produced,” whereby “the material environment helps physically shape my body but the embedded actions in which I engage also transform both the physical environment and the interpretive social world” (2011: 278-279). The individual with a physical disability navigates the physical environment to better manage and control their physical body, while also accepting that their bodies are “no longer the subject of unconscious assumption, but the object for conscious thought” (Howe, 2011: 287). Howe’s (2011) cerebral palsy was his body as ever-present (see also Leder, 1990)⁷; however, he does not necessarily consider this as negative because, he notes, unless we bring attention to the body as a site for

⁷ Leder’s (1990) concept of a “dys-appearing body” (Allen-Collinson et al., 2018: 1334) supplements the body as ever present or the ‘mind-body nexus’ by maintaining that the experience of physical discomfort can disappear from the central focus of the individual when “intentionality [is] directed away from the material body and towards a mental representation, such as the goal summing” (Allen-Collinson et al., 2018: 1334).

lived experience, we will never be able to understand its complexities (cf. Merleau-Ponty, 1962). To better understand disability and impairment, Howe suggested we eliminate “disablist” attitudes (2011: 288; Miller et al., 2004) and in turn, create opportunities for equality. He called for “disability in action” (2001: 288; cf. Dirth and Branscombe, 2019) to explore the impact of having impaired and disabled bodies in social spaces. Howe concluded:

(T)he manner in which our senses interpret how our bodies react to the social and physical environment might go some way to allowing us to understand the relationship between movement and identity that will possibly enable us to get grips with the culturally nuanced interpretations of difference (2011: 289).

Theories of Support

The importance of understanding differences not only allows us the opportunity to redefine normative ideals about ‘fitness’ and ‘ability’ but to realise the absurdity of them. In 2008 Hammer (2015) conducted a year-long ethnography of a cycling group in Israel. The group consisted of both sighted individuals and individuals with vision impairments; other individuals had cognitive or physical impairments. Group members rode tandem bikes, whereby a sighted rider sat in the front and the individual with the [vision] impairment at the back. Hammer examined the “dialogical performance” of tandem cycling as “an encounter that engenders intimate conversations and critical self-reflexive knowledge ... leading to new understandings of *what a body can do* and what a disability is” (2015: 504) [emphasis mine]. Focusing on the sensory body, Hammer sought to understand (re)embodiment, ‘togetherness’ and the fine line between dependency and independency to deconstruct normative ideals and social constructs of body functionality. She also explored how the meeting of different bodies create new meanings that shape everyday life, and illustrates this by considering how “blindness and disability [are] social categories and lived identities that offer an opportunity for enriching our understanding of the senses in general and sight in particular” (Hammer, 2015: 506). Hammer (2015) noted the embodied ways of knowing in tandem cycling, through proxemic intimacy and the bodily engagement of the riders with each other and their environment. Tandem bicycling is a form of tethering, to oneself, one another and one’s environment; I explore this further in my ethnography below. Hammer understood tandem cycling to be an “intersensory performance,” whereby individuals with vision impairments were provided with an opportunity to re-embody sight through a “sensory prism” by which their sighted partner described “the physicality of this experience, as well as their experience

of nature” (Hammer, 2015: 508-509). This enriched people’s experience. Sight became a mutual sensory engagement enriched by other senses available to those with vision impairment (sound, smell and touch). Group members came to think of ‘disability’ as a “bodily experience not defined by the absence of senses, movement or mobility” (Hammer, 2015: 511-512). Tandem cycling, a tethering experience, reinforced the value of embodied experiences of individuals with or without disabilities, so challenging idealised social norms of body functionality to expose the mutuality of shared experiences. This mutuality established not only a sense of shared social community but an awareness of other individuals with unique physical and emotional needs. Hammer noted how “riders often develop not only physical intimacy but also an emotional one, supporting and encouraging each other” (2015: 514). Through this sense of ‘togetherness’ and interdependence, members developed a heightened sense of embodied awareness, both ‘sensing’ their partner and taking responsibility through a critical awareness of “being body-to-body present with others” (Hammer, 2015: 515).

Bi and colleagues (2019) explored the need for more bodily-presence and connection between runners and their supporter/spectators in Long Distance Running Events (LDRE). They found that spectators/supporters wanted to feel connected to ‘their’ runner, offering support by strategically planning their route along the course of the marathon in order to easily spot their runner. However, they would often be upset when their runner passed without noticing or acknowledging them. The spectators/supporters understood the complexity of the running experience, but they wanted to feel connected; in leading up to the marathon, they had developed a team identity or “spectator running identity” (SRI) with their runner (Bi et al., 2019: n.p.). Runners acknowledged the complexity of sharing their experience with their spectators/supporters; even when they experienced moments of extreme struggle and lacked the mental resources to engage with their spectators/supporters, they still wanted encouragement. This occurred even when the need was not articulated – either because they were too focused on adjusting to their own physical needs or because they did not want to worry their spectators/supporters about their state of pain. There were also times when runners would feel as if their spectators’/supporters’ cheering did not meet their physical, emotional and cognitive needs, making the experience of running less enjoyable. Runners found it hard to verbalise their in-the-moment emotions because of how such emotions were mixed with their cognitive coping strategies. In reiterating the complexity of embodied experiences, Bi and colleagues noted that “sensations, emotions and cognitive states are critical to understanding the runner’s experience needs, and not just performance measures” (2019: n.p.).

The sense of ‘togetherness’ created between runners and supporters, or by a tandem cycling pair, can be a complex integration of physical, emotional and environmental factors; in the case of tandem cycling, which did “not eliminate social dependency and asymmetry, but [allowed] the cyclist to learn from other differences as members of a shared community, fostering communal relations of intimacy and trust, while initiating critical self-reflexive knowledge and an awareness of a spectrum of bodily differences and social identities” (Hammer, 2015: 517). The consequent sense of community revealed the interdependent nature of tandem cycling, whilst exposing the emotional and social vulnerability of many riders, irrespective of capability. Hammer (2015) illustrates how such vulnerability is – more often than not – acknowledged and reciprocated by further enhancing the shared multisensory engagement throughout the tandem pairs’ tethered experience. Hammer (2015) noted that the tandem cycling group chose to acknowledge vision impairment and disability as a medium of experience rather than seek to normalise or erase bodily differences. She suggested greater discussion of disability and implementation of accommodation policies (see also Maralack, 2016), especially considering that “we are all dependent on one another as human beings with a myriad of sensory bodies and physical and emotional needs” (Hammer, 2015: 518; cf. Fisette, 2015). As acknowledged by Darcy and Dowes, “the absence of this support [companionship] meant the difference between participation and non-participation” (2013: 400).

Companionship, rather than a desirable digital accessory, comes to be a necessary need in the context of physical activity. The support of [physically] disabled individuals enables inclusion, accessibility and opportunity based on shared experience, and allows individuals to holistically engage with oneself, one’s environment and each other. Such an enriched connection and sense of embodiment cannot – and should not – be mediated by the mere accompaniment of a (bio)technological device.

From the literature reviewed, I adopted a progressive analysis from the history of fitness to the implications of utilising (bio)technology to better understand our bodies, through a framework of disability and [physical] impairment. This approach allowed me to appreciate the importance of the lived sensory body, in relation to itself and its environment, including other physical bodies. This helped me to understand the need to reconfigure “assistance” and “support,” not as defined by either social or algorithmic configurations but by the experiences of (i) embodying forms of subjective knowledge, (ii) (inter)sensory engagement, (iii) physical self-perception and the (iv) mutual exchangeability of motivation, community and company that present opportunities for better assistance and support in sport. This research report illustrates

the importance of assistance and support through a narrative analysis of embodied experiences by athletes with and without physical disabilities. I juxtapose this with acknowledgement of various forms of assistance, from (bio)technology to physical bodies supporting and guiding others.

Methodology

I adopted a qualitative approach in my research methodology, as the most effective means to gather personal narratives and descriptions of the embodied experiences of my participants. I wanted to present a narrative account of my participants' lived experiences as sensory sporting bodies while understanding the individualised sense of embodiment (Howe, 2011; Fisette, 2015; Hockey and Allen-Collinson, 2015)

On 14 March 2019, I received confirmation that I would be running the New York City Marathon (NYCM) on Sunday, 3 November 2019 as a support guide for an individual with a physical disability. I would be one of five performing this rewarding task. I was offered the opportunity through my brother, who was participating as an individual with a physical disability, and my father, who would be my brother's support guide. Our participation was made possible by an organisation known as Achilles International,⁸ which supports individuals with disabilities to participate in mainstream sporting events – an example of Lindemann et al., (2017) argument for such organisational movements – NYCM was one of these events. I wanted to engage more deeply with this organisation, acknowledging its inclusion of individuals who are often denied the opportunity to participate in mainstream sporting events (Shapiro and Martin, 2010; Howe, 2011; Fisette, 2015; Darcy and Dowes, 2013; 2015; Hammer, 2015; Darcy et al., 2017; Elman, 2018).

My decision to study the organisation and two of the marathon's five disabled participants was influenced by my desire to better understand the relationship between sports participation and disability theory. An individual with a [physical] disability experiences numerous constraints depending on their various assistance, accommodation and support needs (Abdullah et al., 2008; Darcy and Dowse, 2013; Maralack, 2016; Darcy et al., 2017; Zeagler et al., 2018). I had established that (bio)technology, or [digital] “assistive technology,” would not be able to monitor these various needs (Toner, 2018; Bi et al., 2019). My curiosity grew to better

⁸ Achilles International or formerly known as the ‘Achilles Track Club’ was founded in 1983 by Dick Traum. It is an international organisation, with its headquarters located in New York city, and provides support, training and technical assistance for individuals with various disabilities who wish to participate in mainstream athletics and running events. [<https://www.achillesinternational.org/>]

understand how individuals with [physical] disabilities realised their aspirations of sports participation, to study the mediating and facilitating role of the organisation, and to describe the experiences of individuals running and hopefully successfully completing the marathon. The embodied sensations and experiences of the sensorial sporting body are mediated by numerous factors (Howe, 2011), including intersensory engagement (Hammer, 2015), physical self-perception (Shapiro and Martin, 2010; Scarpa and Palumbo, 2017), embodied knowledge (Hockey and Allen-Collinson, 2015; Allen-Collinson et al., 2018) and systems of support (Dowse and Darcy, 2013; Bi et al., 2019). The value of being with another individual can enrich the running experience of the individual with a disability (Darcy and Dowse, 2013). I wished to understand the individual's body as a site of different sensory modalities by optimising the capabilities of the individual relative to their strengths (Abdullah et al., 2008), through active monitoring based on the in-the-moment mentality of lived experience (Hockey and Allen-Collinson, 2015; Allen-Collinson et al., 2018). I was interested in how this fostered a sense of connectedness and community through support, encouragement and motivation (Hammer, 2015; Bi et al., 2019). My experience as a support guide and my engagement with my participants allowed me to realise that an objective "unbodied" (Smith and Vonthehoff, 2017) digital (bio)technological device has yet to fully encompass and include in its forms of assistance the nuances of what it means to support the sensory sporting body and its lived experience, despite physical constraints, limitations and impairments.

I began my research by identifying people who I wished to involve as "co-contributors" (Lindeman et al., 2015) to my research. Inclusion was based on three criteria: (i) individuals who engaged in some form of sporting activity and/or participate in social sporting events, (ii) high functioning individuals with physical disabilities who were running in the upcoming 2019 NYCM, and (iii) individuals who were to be support guides or form part of the support systems (cf. Bi et al., 2019) for the NYCM participants. My intention to include three different groups of individuals reflected my desire to collect diverse experiences of and notions about embodiment. This included what it means to utilise and provide assistance and support from either a (bio)technological device or being in body-to-body presence with others – both receiving and offering in-the-moment support (Hammer, 2015; Bi et al., 2019).

Understanding that some of my participants have physical disabilities, I took special consideration and pre-emptive measures. I decided to involve both my brother and my running partner – for whom I was support guide – as the main "co-creators in knowledge" (Lindemann et al., 2017: 6), and to understand and acknowledge my familiar and personal relationships with

them. I felt confident in neither misrepresenting nor misinterpreting their individual experiences. Before I could begin engaging with my brother or running partner, I wanted to speak to them about the challenges surrounding the terms “impairment” and “disability.” Lindemann and colleagues (2017) reiterated the importance of needing to understand an individual with an impairment and their self-understanding through the use of language, particularly the terms which they use to self-identify. My understanding of each term derives from my engagement with the literature reviewed, and my experience as a sister to someone with a [physical] disability. The terms are often used synonymously to refer to either a functional or physical limitation, acquired or congenital, with ensuing social consequences (Scarpa and Palumbo, 2017; Dirth and Branscombe, 2019). I took some time to figure out what was meant exactly by each term, understanding their differences and acknowledging their similarities. I understand “impairment” as either a physical and/or functional limitation that is either congenital or acquired (Anastasiou and Kauffman, 2013; Lindemann et al., 2017; Scarpa and Palumbo, 2017) and “disability” to refer to its social, political or economic effects, such as lack of opportunity to participate, lack of enabling policy and acknowledgement for personal dignity, including constraints on participation in sports (Darcy and Dowes, 2013; Darcy et al., 2017; Dirth and Branscombe, 2019). Lindemann and colleagues (2017) reiterate the importance of language when referring to these individuals, noting how the terms “disabled individual” or “impaired individual” are reductionist and place importance on identifying the condition of the individual before acknowledging their personhood, whereas “an individual with a disability” or “an individual with an impairment” emphasises the subjectivity of the individual by prioritising their humanity before their condition/category. The NYCM identifies individuals such as my brother and running partner as ‘Athletes with Disabilities’ (AwD) (cf. Fisette, 2015)

In contrast, both my brother and running partner added a third descriptor which they found more inclusive – “differently-abled” (cf. Maralack, 2016), describing an individual with either physical or functional limitations (impairment) who was able to overcome its associative challenges (disability) by being able to be socially included although through different means, whether through a simple mindset shift or the aid of a support guide. In an interview with my running partner, I asked which term he believed best described him:

I think an “impairment” is possibly the worst word I’ve heard in probably a while, that just sounds so bad. I don’t know, but “impairment,” I think ... I see my TBI as *an ability*, it’s as if God has, came down and he, he pushed me off my bike, and he said,

“I told you, I’ve been telling you all your life, you’ve got an ability and you’re not using it, now I have to force you to use it” and I believe it happened to me because so that I can help other people. I feel no pain or displeasure in it, I think that I have been pushed into this by God, my God, to now flippin’ do what he asked me to do. [emphasis mine]

Fisette (2015) contested identifying as “disabled” because she felt she could complete the marathon without aid or assistance; she makes “assistance” appear as if it were further disabling her from participating in mainstream sporting events. It did not support her desire to pass as an able-bodied athlete, which was her previous “performance identity” (Fisette, 2015). I decided to accept this re-identification and acknowledge its importance, and to use it in my analysis and narration of both my brother and running partner’s embodied lived experiences.

I then proceeded to identify other key participants. One was my father. My decision was twofold. First, he actively used digitised “assistive technology” – a Garmin watch – especially when training for the NYCM. Second, he was the support guide for my brother, and because of their relationship, he could make informed assistive recommendations suited to my brother’s “impaired” form of running. He was also the main supporter and enabler of my brother’s potential leading up to and throughout the marathon, learning from the experience of running with an “impaired” yet familiar body (Darcy and Dowse, 2013).

Through snowballing, I recruited three more participants: one had recently run the 2019 Comrades Marathon; one was an aerobics instructor; and one within the last six months had undergone knee replacement surgery and was currently undergoing rehabilitation. All three had used some form of “assistive technology,” although each had a different form, and different intentions and conceptualisations. In total, I had six participants: two were physically impaired; one was a support guide; two were physically active; and one was currently uncertain about their physical self-perception and was in the process of re-embodiment, familiarising herself with her new physical capabilities following surgery (Shapiro and Martin, 2010; Hockey and Allen-Collinson, 2015; Scarpa and Palumbo, 2017).

Having agreed to participate in the study on an understanding that anonymity cannot always be guaranteed, some participants gave pseudonyms as per our agreement on consent; others, due to our personal relationship, have not been anonymised. I made this decision cautiously after discussing it with my supervisor and with the participants. I realised the impracticality of anonymising my brother and father, and we all three agreed for me to refer to both of them by their first names. This allowed me and readers to acknowledge their roles without the familiar

relationship interfering with my professional role as a researcher. My running partner, once I presented him with the Consent Form (Appendix D), decided against being referred to by a pseudonym because he felt that his journey, from his accident to completing the NYCM, was a story worth telling. Practically, it would also be difficult to guarantee his anonymity given the broadcasting of the marathon and social media posts, and he regularly referred to me by name in his blog as his [support] guide.⁹ To avoid possible deception and potential harm, in agreement with these three participants, I refer to them by their actual names; those for who I use pseudonyms are indicated at first mention with an asterisk (*).

Bevan experienced a motor vehicle accident five years ago (2015), leaving him with left-sided hemiplegia and a TBI. He participated in the 2017 NYCM and later the 2019 NYCM, with me as his support guide.

Natalie* is able-bodied and lives a physically active lifestyle by going to the gym and facilitating cardiovascular training programmes. She makes use of a heart rate monitoring device to track her physical performance.

Amanda* is an able-bodied individual who lives a physically active lifestyle and uses a Polar watch to monitor her physical activity. She is part of a running community that tracks their group's performance on the online app Strava. When we met, she had recently completed the 2019 Comrades Marathon.

Vanessa* was unsure of how to identify. In the previous six months, she had undergone knee replacement surgery and was, when we spoke, undergoing post-surgery rehabilitation. Before the surgery, she had used a Garmin device but now found it impractical as it did not take into consideration her "new" body and its "new" capabilities and limitations, especially because her only form of recommended physical activity is swimming.

Toni is able-bodied and lives a physically active lifestyle by going to the gym. He trained for and successfully completed the 2019 NYCM. He was Nick's support guide in the NYCM, and is Nick's and my father.

⁹ Bevan's blog, *My Broken Brain*, can be read by visiting: <https://mybrokenbrain.co.za/>

Nick had a motor vehicle accident in 1997, leaving him with right-sided hemiplegia and a TBI. He successfully participated in the 2019 NYCM with Toni as his support guide. He is also my brother.

I will also mention other people in this report, but I did not formally interview them. All were involved in the Achilles International and NYCM experience. They include Bevan's wife, who helped Bevan understand and answer my interview questions, another athlete with a disability who utilised a handcycle to participate in the NYCM, another South African support guide, and an American support guide who also assisted Bevan to participate in the marathon. In total, 15 individuals from the South African Achilles chapter shared in this experience. Five physically disabled individuals participated in the marathon, five were designated support guides, and five individuals were family members and an integral support system for both participants and their support guides. The 15 of us became a supportive unit: we stayed together, ate together and marvelled in this shared opportunity.

My participants had more in common than they had differences; each participates in some form of sporting activity while utilising some kind of "assistance" – a digital wearable device to actively monitor and track their performance, embedded modified titanium to better one's physical capacity, or the bodily-presence of another individual to share in the experience. The nuances and forms of support and assistance are subjective and should be treated as such by avoiding algorithmic configurations, standards of physical capacity and neoliberal ableist agendas.

I adopted five main ethnographic instruments in my research process: (i) semi-structured interviews, (ii) participant observation, (iii) ethnographic journaling (iv) participant diaries and (v) auto-ethnography.

Semi-formal interviews

Having identified my six key participants, I contacted each regarding participation in my research. I utilised both my personal networks and instant messaging through SMS or WhatsApp or formally emailed my participants, depending on the nature of our relationship. In each initial communication, I introduced myself if the individual did not know who I was, then mentioned in an Information Sheet (Appendices A, B and C) my research aims, intentions, and methods, reiterated and discussed both consent and anonymity, and invited them to participate. I would end each (in)formal communication by reiterating the need for the individual to carefully consider the invitation before accepting, by mentioning any possible

risks or potential harm, and how I proposed to avoid and deal with them. Considering the differences among participants, each required their own Information Sheet (Appendices A, B and C); each sheet had the same information regarding my research aim, objectives and methodology, but differed in possible risk and potential harm. Understanding that my two participants with physical disabilities might be exposed to a research setting that might result in re-traumatisation, I sought to carefully consider the manner in which I presented this. Each individual responded almost immediately and without hesitation to participate. Once I received their confirmation, we arranged a time and place to meet that did not interfere with personal or work commitments. At the outset, I presented each interviewee with a Consent Form (Appendix D), which detailed the requirements of the interview, agreement to be audio-recorded, and emphasis on anonymity through the use of pseudonyms. Once we had both signed and dated the form and possible questions and concerns were addressed, our interview began. All participants consented to have the interview recorded; each recording was saved under the date of our interview, initially stored on my passcode-protected mobile device, and then transferred to my security protected laptop.

I began each interview by asking the participant to narrate their sporting journey, from its inception to the present. I inquired about what they understood by the term “assistance” and whether or not they utilised a form of it. Each participant responded differently: using (bio)technology, such as digital wearable devices, or using embodied knowledge and bodily presence as a form of acquiring assistance. Subsequent questions varied depending on their responses. Throughout the interview process, I noted the participants’ individual opinions about “assistance,” sports participation, and physical self-concept, further investigating the nuances of their lived experience. Responses led to new questions and clarifications, possible agreement or contestation with the reviewed literature and potential questions for other participants. Once I felt as if my participant had answered the questions presented and had narrated their personal experiences in as much detail as agreed, I asked whether they would agree to a follow-up interview if I felt further clarification was needed; although each participant agreed, no follow up interviews were arranged. When I and my participant felt confident in both our questions and responses, the interview formally ended, and the audio-recording stopped. I then transcribed each interview, saved under my participant’s chosen pseudonym and/or name with the date of the interview. These transcriptions were core data for analysis.

Participant observation

I based my participant observation on my marathon training and the marathon journey itself. Training included engagement with Bevan and observation of the ways in which Nick and Toni were preparing for the marathon, learning more about themselves and each other, and navigating mutual assistance and support (Hammer, 2015). The marathon journey included events leading up to the marathon, a dinner and the marathon itself.

From confirmation to participate in the NYCM, we – Bevan, Nick, Toni and I – decided to form a “team,” with regular training sessions and weekly meetings leading up to the marathon. Training included scheduled weekly runs, social sporting events such as ParkRun, and one half-marathon (Gerald Fox Memorial Half-Marathon). Participating in training allowed me to become physically stronger, fitter and mentally prepared to run a 42.2km marathon (26.2 miles), which is the total length of the NYCM (Appendix E), and to engage with and observe different bodies in action (cf. “disability in action” in Howe, 2011; Dirth and Branscombe, 2019). I especially noted the ways in which [disabled] bodies engaged with other [abled] physical bodies (Hammer, 2015), their immediate environment (Hockey and Allen-Collinson, 2015), and the manner in which they utilised their embodied knowledge to better their performance (Hockey and Allen-Collinson, 2015; Toner, 2018; Allen-Collinson et al., 2018). Each observation and engagement revealed different sites of knowledge, ranging from negotiating my own physical self-perception to examining Toni’s relationship to both his Garmin and to Nick, noting how the device became a mediating and influencing factor in how he monitored Nick’s performance; from questioning and figuring out how to be a support guide to simply observing the importance of physical sensations in our interpretation of bodily performance and bodily knowledge. Each training session afforded me an opportunity to understand how to be a support guide and to acknowledge the importance of what support means to different bodies – having another individual telling you to push harder or commenting on your breathing patterns because they know from experience that that is where you struggle.

Ethnographic Journaling

After each training session, I would reflexively and reflectively engage in journaling, recapping my experience of running or recalling my running journey, and tracking the progress of my thinking as a researcher participant about “support” and how it is being negotiated, offered, rejected, ignored or inaccessible when needed (Bi et al., 2019). However, as I discuss below, even ‘sufficient’ training does not adequately prepare you for a marathon. Running 42km

requires more than being able to actively monitor your heart rate. After each interview, training session and the marathon itself, I engaged made notes in the journal of my thoughts, opinions and questions that arose from these engagements. I took particular note of my experience as a support guide and the process I endured to understand how to effectively become a guide, and to understand the importance of being a guide as an enabling factor in a seemingly inaccessible activity (Fisette, 2015; Hammer, 2015). I noted my observations on Toni and Nick, examining the ways in which they became physically and mentally fit for the marathon; I reflected on how this was translated when actually running the marathon, how they came to understand and accept the role of interdependent support and assistance, and how they negotiated with each other to provide and accept it (Hammer, 2015). I would often journal about my experience of them running, assuming that their relationship was modelling the runner-guide relationship, providing a framework which I believed I needed to follow. However, as soon as I started journaling my weekly meetings with Bevan, I realised that the only way I would know how to be an effective support guide was to understand and acknowledge his individual support needs (Darcy et al., 2017); these could not be learnt by observing anyone else. I thus came to journal and record the new information I learnt about Bevan – aware of his asthma, the importance of having his asthma pump, and his engagement with other participants of the sporting events, which was both tiring and a distraction from his focus on running. Through journaling, I was able to reflect on his lived experience as an individual and a sporting body. Journaling somewhat prepared me to become a successful support guide to Bevan for the NYCM. However, it did not prepare me enough for what to expect, as supporting Bevan took away from my ability to support myself and to be effective in my overall ability to guide and support him. I decided towards the end of my research to reflect on and journal about being a sister to an individual with a physical impairment; I found this quite difficult as it required me to engage on a more personal level. However, the importance of adopting a subjective approach to my analysis emphasises that I bring to my research a set of lived experiences, with a ‘voice’ that can further elevate the “standpoint epistemology” (Howe, 2011) of my research (Fisette, 2015). Hammer referred to her positionality and the fine line between researcher and participant, and understood the value of journaling her experience as both: “My sensory body informed the ways I documented, interpreted, and conceptualized the group’s activities, and my fieldwork journal is replete with descriptions of my somatic experiences” (2015: 508). This acknowledgement allowed me to realise and validate my approach towards journaling as a researcher and support guide, as my embodied experiences of support allowed me a richer understanding of my analyses.

Participant Diaries

I also asked both Nick and Toni to consider journaling – not only to assist me in analysing the narration of their experiences of training for and running the NYCM but also because I considered journaling to be helpful. Journaling provided me with an opportunity to better understand my own physical capabilities and acknowledge the importance of support and its mutual exchange between bodies (Hammer, 2015). Bevan was already writing about his experiences in his blog. Nick decided to partake in the exercise; Toni found it quite difficult to engage and effectively put his experiences into words; I return to this in Chapter 6. Nick consented to have me read and use his journal to supplement interview and observation data.

Autoethnography

From engaging with my own journaling and running experiences, and my relationship to an individual with a physical disability, I decided to begin my research report autoethnographically. Hence my narrative account of my experience with Nick when he “almost” summited Mount Kilimanjaro. Both Toni and I were there with him, and this provided the foundation to my desire to conduct this research and better understand the complexity of support that goes beyond digitally calculating heart rate relative to MASL.

As noted above, writing in a manner that presented my subjective experiences and reflections on my research successfully illustrated the personal sentiment and nature of understanding individuals who are similar yet in different capacities to both the writer and the reader (Howe, 2011). This stylistic decision was advantageous insofar as the writer illustrates – without distortion and overt integration of the self – the complexity of understanding human engagement both individually and collectively. From the autoethnographic (Howe, 2011; Fisette, 2015; Hammer, 2015) and autophenomenological (Hockey and Allen-Collinson, 2015) literature reviewed, such a subjective and reflexive approach serves an epistemological necessity (cf. “standpoint epistemology” in Howe, 2011).

Writing from a first-person perspective, I experienced moments of doubt when it came time to critically engage with my own journaled reflections and reflexivity, both as a researcher and a participant in my own research. I struggled in identifying the gap between myself as an observer and myself as a subject. This constant mediating between my two prescribed roles interfered with my analysis during my fieldwork; however, upon assessing my collected data, I came to realise the powerful bridge I can mend across this divide. Writing auto-ethnographically and auto-phenomenologically allowed me the opportunity to engage more deeply with the

complexity of my research interests by experiencing the insightfulness of embodied knowledge, the navigation of self-identity, the richness of intersensory engagement, the need for shared human connection, and the validation of interdependence despite and because of differences.

Ethics

Before I conducted my research, ethical clearance was approved by the Department of Social Anthropology at the University of the Witwatersrand, Johannesburg, and the Human Research Ethics Committee (HREC) of the university. My main responsibility was to ensure that my participants were not placed in any potential harm. I read and familiarised myself with the ethical guidelines set out by the Anthropology Southern African (ASnA) and the Wits Code of Ethics.

Once I had briefly discussed the objectives, aims and methods of my research with my participants, a written consent form (Appendix D) was presented to them, detailing the requirements of participation, agreement to audio-record, and the opportunity to use a pseudonym. I reiterated that participating in my research would not interfere with their personal and/or work commitments and that they were not obliged to continue if they felt the need to withdraw. I stressed that such a decision would not result in any negative consequences and would not be mentioned in my final Masters' research report. None of my participants felt the need to withdraw.

As already described above, having acknowledged my personal relationships with three of my key participants and the nature of the event in which we were engaging, I understood that anonymity could not be guaranteed. I had discussed the implications of referring to them by name, noting a possibility for further stigmatisation, marginalisation and discrimination – particularly for Nick and Bevan. I also knew that I would be making them “co-creators of knowledge” (Lindemann et al., 2017: 6) and that I would actively engage with them about how I wrote about them. Before entering the research process, I knew my intention, objectives and aims were not to discuss the cause of physical impairment of my participants, but to engage with questions of their self-identity, experiences and narratives as sporting bodies, irrespective of their physical limitations. There was a possibility of eliciting moments of traumatic recollection, although I did not intend for my questions to provoke this. I was aware that Bevan and Nick would refer to the cause of their physical disability to best describe their experiences and narratives of embodiment. Whenever this occurred, I made sure I stopped the interview

process and inquired whether they were willing to share their experiences and if so, I would mention and reiterate the importance of seeking professional psychological counselling if they found this distressing in any way. Both Bevan and Nick are currently involved in a counselling organisation which they regularly visit; however, I still reiterated the importance of seeking professional counselling. If at any time either Nick or Bevan felt overwhelmed about what they were telling me and brought my attention to it, I would pause the interview and ask whether they wished to continue, reiterating that they are not obliged to do so if they felt the process to be emotionally and personally demanding. Neither felt the need to relinquish their participation in my research; however, they did and still do attend professional counselling sessions.

Because of my personal relationships with three participants, I was particularly conscious to maintain as professional a role as possible. I decided that if this relationship posed a potential threat to the nature of my research, then I would intervene through active discussion, addressing the importance of my potential findings and analysis, and discuss what implication and significance this could have on a broader area of research. No intervention was needed.

Given Nick's and Bevan's physical disabilities, and acknowledging their opportunity to participate in the 2019 NYCM, I wanted to narrate their experiences as sensory sporting bodies, not bodies physically limited or socially disabled. I decided to focus on their active ability through adversity. I constantly mentioned to them that I would refer to them mainly as athletes with physical impairments, not as people with disabilities. Upon reflection, however, the NYCM refers to athletes with various impairments as "Athletes with Disabilities" (AwD), thus changing my decision to conform to this use. My argument is in line with Fisette (2015): If they do not see themselves as sporting bodies, then, what and who is a sporting body?

My reflexive fieldnotes and journaling fully encompassed what it meant to be a sensorial body with a set of lived experiences, rather than to be a researcher seeking to understand how sensory bodies are meant to be experienced. My intention to actively and reflexively journal was made to better understand the relationship between myself *and* other sporting bodies – irrespective of bodily capabilities, and not myself-in-relation-to-other-sporting-bodies. I sought to journal not about how individuals with physical disabilities are constrained (Darcy and Dowse, 2013; Darcy et al., 2017), marginalised or stigmatised (Ruckenstein and Schüll, 2017; Lupton, 2017) in mainstream sporting culture. Rather, I wished to understand how they navigated their bodies as adaptable sites of capability and their need for assistance beyond that of (bio)technological

devices. Journaling allowed me to see them as “differently-abled” athletes and I accepted the various forms of support and assistance they utilised to participate in social sporting events.

Wider Significance

My research explores the complexity of being human, especially in relation to the ability and disability divide. This divide is implemented by neoliberal agendas and (bio)technological advancements, including within the domain of sports. By reviewing the literature, engaging with physically active individuals with varied capabilities, and participating in the 2019 NYCM, I argue the need for reconceptualisation, better acknowledgement and openness to rethinking what it means to “support” and “assist” individuals. I focus on those who defy the social ideals of ableist physicality and sports participation, individuals with [physical] disabilities, and notably within the Global South (see also Comaroff and Comaroff, 2012). I aim to engage with what alternative forms of assistance and support are utilised by these individuals and how these go beyond the numerical input and output systems of digital assistive (bio)technology. What it means to be human encompasses the ability to foster relationships with oneself, one’s environment and one another.

Chapter 3: Embodied Subjective Knowledge

“I think the one constant between *everybody* is that everybody has a heart, and everybody’s heart can be monitored” (Toni, 27 July 2019)

Introduction

The rise and utilisation of (bio)technological devices to better understand our bodies have supported the embodiment of ableist ideologies (Elman, 2018). We have seemingly become tethered to such devices and detached from our physical selves and the complexities associated with it (Smith and Vonthehoff, 2017; Toner, 2018; Rapp and Tirabeni, 2018). Has this fixation with determining one’s physical performance against a predetermined algorithm mediated such complexities of the human experience? Have we become “algorithmic bodies” (Yang, 2014) and if so, what remains of the nuanced human body? An understanding of how we engage with our bodies in its entirety needs further exploration. As Burkett and colleagues (2011) suggest, does our newfound dependence on technology within the sporting domain inhibit the independency of being human and the interdependency as part of the human being experience? (Hammer, 2015) Engaging with narratives expressed, interviews conducted, and experiences shared, in this chapter, I aim to explore the value of embodied subjective knowledge and how it is being influenced by “unbodied” digital data (Smith and Vonthehoff, 2017). (Bio)technology can become a mediating factor for sports inclusion for everybody, however, without necessarily taking into careful consideration every body (cf. Zeagler et al., 2018; Elman, 2018).

Tethered

Our dependence on external devices such as wearable biotechnologies including smartwatches and heart rate monitors has become part of our body over time and with prolonged use of them in our training and fitness regimes. They seemingly reveal intimate details about ourselves which we never knew before. We become attached to them and them to us; but what are we detaching ourselves from in their place?

With the power of such technologies as mediating factors in our physical activities, we recognise the pleasure in them and the potential in ourselves; as expressed by Toni from his experience with his Garmin smartwatch, “it is nice to track what *actually* happens as opposed to what you felt or what you thought was happening” (see also Toner, 2018). The device in and

of itself becomes an incentive not only to become fitter but to actively track your fitness progress. Both Natalie and Amanda shared the same sentiments about their devices, a smartwatch and heart rate monitor respectively. Natalie wanting to monitor her progress and performance in order to gain a better understanding of herself, and Amanda tracked her progress to become more competitive with herself. This incentive to better oneself through self-competition is a motivating factor to use such devices (cf. Rapp and Tirabeni, 2018). We become attached to this desire for betterment as reflected through trends and patterns visually represented in graphs. Toni reiterated that the device provided the “facts” about one’s physical potential instead of basing one’s physical capacity on “feelings,” which he believed provided excuses for underperformance. Thus, the device becomes a means to better recognise one’s potential as predetermined by algorithmic datasets, by dismissing “false” perceptions and assumed inabilities as determined by our feelings in-the-moment of physical activity. The device becomes assistive in that it allows for extrospection based on the standard of one’s physical performance, without the possibility or need for introspection. However, at what point could introspection become vital to better understanding one’s performance and what did Vitality have to do with it?

Each of these participants mentioned their membership in Vitality, Discovery Insurance’s¹⁰ wellness programme. The programme incentivises its clients to monitor and track their physical activity through the use of biotechnologies such as smartwatches and other wearables, but also to keep a record of their fitness progress and sharing this biodata with the company (cf. Lupton, 2017). Agreeing to openly share such data and meeting predetermined fitness goals are rewarded with lower insurance premiums, lower hospital costs and the occasional discounted jacket, as Amanda wore at our interview. Not only did the user become “in sync” with their health, but so too do their insurance company wherein the user synchronises their biodata from the day with their chosen online fitness applications, which the insurance company can access. The incentive was successful in that it formed part of the strive towards goal attainment, much like the ‘endurance work’ of high-altitude mountain summiting (Allen-Collinson et al., 2018). As Toni explained:

Human beings by their very nature require some form of short, medium, and long-term incentives to do things they understand are good for them but don’t necessarily always

¹⁰ Discovery Limited is a South African financial service company which started in 1999. They offer medical aid, car and life insurance as well as wellness incentives (Vitality) based on their clients lifestyle behaviours. [<https://www.discovery.co.za/portal/index.jsp>]

... do them, and by creating an incentive that is monitored and managed ... will be good for you – good for that particular individual.

It is good to reach the mountain's summit and it is good to be rewarded for achieving a rather standardised goal – provided you form part of the generic demographic of intended users. To do this, one needs to be able-bodied; otherwise, the incentive is not intended for you or is seemingly unattainable (cf. Elman, 2018). As much as we become tethered to our devices for physical progress, so do our devices through incentivisation become tethered to us. Through this, those who can meet the predetermined data sets – which Toni claims to be based on a “law of averages” – are rewarded; those who cannot meet the reward are further marginalised (Lupton, 2017; Ruckenstein and Schüll, 2017). Vanessa, also a Vitality member, expressed her frustration with the goal system of the programme, especially considering her new physical self and its associative capabilities. She noted how the programme was generic and favoured those who walk and run as a means of physical exercise (cf. Elman, 2018 on step counting as a gatekeeping metric). The limited use of her Garmin smartwatch before and briefly after her knee surgery was motivated by the incentives of the programme rather than for her own self-betterment. She knew that the amount of effort she would painstakingly put into physical activity would be inadequately reflected in the steps counted and heart rate measured by the device. When I asked her what she would change about the device and the programme, she replied:

If they could take into account what *my* personal best is – not what *they* dictate it to be, my personal best could be like what you said, 800 steps a day and I could be sweating, and my heart rate going and that for me is, “wow, I’ve achieved something”... so why not give me a personal best based on *my* capabilities, and I *will* achieve it, and I *will* meet it, and I will be able to get the rewards as well. But at the moment I do not get the rewards and I don’t get all the benefits because I do not meet *their* ideal, I don’t meet *that* criteria.

Such personalisation according to Toni is only meant for an ideal world. Individuals can either become tethered to the desire for self-betterment through incentivisation or stay tethered to the ideals of self-betterment that are seemingly unattainable, a disincentive from personal and physical achievement. We thus disengage from our own physical capabilities by basing our potential on predetermined data sets. Such devices, intended for everybody, are in fact inconsiderate of every body.

“everybody... *every body*”

With Toni’s approval for such incentivisation as an added motivation to exercise and Vanessa’s dismissal of further use of her device because of its predetermined datasets, Natalie’s opinion formed a middle ground in this debate. She mentioned how her heart rate monitor reassured her of her physical performance and progress, but she also considers how such assistive devices are subject to one’s needs and the device’s capacity to accommodate to them. One becomes responsible for one’s own physical performance. Natalie further mentioned how “relying on an external factor to motivate you to do the right thing for yourself is in itself just wrong,” but then in contradiction claimed that “sometimes you just need a standard to say that this is how you should be, and what you should be doing.” This is just how the world works. But having an external device determining what you should be doing and how you should be doing it must at some point remove the internal motivation to make one’s own judgements and decisions (cf. Toner, 2018).

The device confirms the notion of being *a body* and in being part of *everybody* else in accordance with a body of algorithms. Vanessa’s decision to relinquish her use of her Garmin watch was effective because the watch failed to capture her ability to physically perform following her new (re)embodied capabilities (Fisette, 2015). Natalie explained that some individuals might not consider such devices because “they think of it to be something that is quite far off their goal.” Individuals become responsible for their physical activity when they are accountable for what assistive measures they utilise. The ability to choose is there, despite the incentive; it is dependent on individual goals, physical capacities and personal capabilities.

Vanessa knew that wearing her Garmin watch would distract her from enjoying swimming by focusing on “chasing numbers,” displacing the motion of the body into quantifiable data. Vanessa’s goal was to take better care of herself through her new performance identity (Fisette, 2015):

I’m doing for *me*, I do it for *my* well-being, for *my* – to make *me* feel good about myself, to make me feel that I’m taking the second chance that I have been given with my knee and using it, putting it to good use ... I would rather *enjoy* my hour than try to chase the next number from my data at night.

This desire for enjoyment out of self-interest is not common between *everybody*, especially when it comes to bodies that are not part of the “law of averages.”

I had asked Nick about his training for the NYCM and whether he used any form of an assistive wearable. His answer was simply “no.” But in his journal, he elaborated on this:

People sometimes tell me why don't you wear a watch? I tell them I live in the now and take whatever comes your way, cause the past is history the future a mystery but this moment right here is a gift that's why we call it the present. (21 July 2019) [unedited]

The ability to live-in-the-moment and embrace this subjective immediate experience cannot be rendered into objective data. During our interview, this essence of being-in-the-world was not brought into my consciousness (Merleau-Ponty, 1962; Howe, 2011). Toni offered a response to explain Nick's “no”. He argued that as Nick's support guide for the marathon and coach for the training programme (Abdullah et al., 2008), “there is no real necessity for him to have one if I'm monitoring his progress.” The external device might be “absent” on Nick but its features of tracking physical progress by keeping [tangible] records were ever-present and embodied by proxy on Toni's arm. This became problematic as Toni's monitoring of Nick's physical performance was mediated through his Garmin, which was monitoring Toni's own progress. Nick's body was removed from consciousness and rendered into distance covered, pace maintained and duration of the activity. Toni's justification was to be clear about “whether we can *actually* achieve the goal [crossing the finishing line].”

Toni explained that he was monitoring Nick's physical performance on his behalf because of Nick's physical challenges, which could result in inaccurate performance results were Nick to wear his own device. However, basing one's physical performance on such a measure detaches the complexity of the experience from the activity itself. Nick would often struggle to keep up with Toni as his gait would impinge his stride and his breathing would become laboured. As much as monitoring one's physical performance is about endurance, it was also about getting to the finishing line. It now seems that technologies such as smartwatches and heart rate monitors do not assist in a better understanding of human experience in performing physical activities, especially the body that is disabled.

Toni could have better understood Nick's experience of running by engaging subjectively rather than superimposing through mediation what it can and cannot do. By *factually* determining Nick's performance alongside what he should be doing, Toni detached the body as lived experience in terms of what it was *actually* enduring.

Mindful vs. Mind-full

By shifting focus away from predetermined facts and towards in-the-moment feelings, are we better equipped to understand the human body holistically (cf. Saw et al., 2016; Gabbett et al., 2017)? Having our performance goals already determined for us, we become less motivated to engage with what our goals might be. We become so preoccupied with this want to attain self-betterment that we become unsure about what we want to better and how. Vanessa expressed her feeling of “inadequacy” when I had asked her opinion about participating in local ParkRun events. She suggested that “privileged” runners are inconsiderate of walkers like herself, as “they are chasing something,” whether this ‘something’ was from a previous event or acknowledgement from their device or others. The social mindfulness of the activity was hindered by the individualistic mind-fullness created by such devices. This motion of “chasing numbers,” as Vanessa termed it, becomes a powerful analytical frame for one to realise and recognise within themselves what is truly being sought after.

By taking our bodies and the self out into the periphery of our overall physical performance, we neglect to listen to our bodies and be mindful of ourselves in relationship with, and not in relation to, others. Despite Toni’s contestation of bodily intuition as “an excuse for you to underperform,” intuition does offer the opportunity to help better the performance of others – whether by acknowledging their personal triumphs or assisting them in their struggles. As much as the runners of the ParkRun event strive to achieve [personal] goals, they need also to remember that other runners and walkers are working towards their own goals. This becomes challenging when our ideals of betterment conflict with ideas of what needs to be bettered by others.

Amanda shared her experience of running with members of her running community. After accepting that she might not be as fast as her husband or other members, she did, however, want to make sure that everyone else knew that too. When she was training for the Comrades Marathon, she knew that she was “the slowest in terms of training, so when we’re going somewhere, I say, ‘I know the route you guys. If you look back and can’t see me, I’m perfectly fine, go with *your* pace, I *am* coming.’” What Amanda wanted from her running community to help her perform better was not to wait for her, because she also knew that one “shouldn’t depend on them – if the group didn’t show up, what’s going to happen?” Dependence on others to better oneself can become problematic in terms of personal goal attainment. Vanessa refused assistance from a personal trainer during physical rehabilitation. She preferred not to listen to

commands being shouted at her “by somebody who has *no* clue what I’m feeling or what *my* body is capable of.” As much as Amanda would rather run at a pace that is comfortable for her, Vanessa’s preference lies in listening to her body as she, “*know[s]* my body, I *read* my body, and I *listen* to it and I accommodate to it.” The manner in which we both give and receive mindfulness should remain independent of the mind-fullness associated with ideal goals and standards of performance. However, had Amanda a running partner with a similar running pace or Vanessa a swimming coach familiar with her experience, they could potentially become simultaneously dependent on and independent from how they actively engage with these individuals. In establishing a sense of connection between human beings with a shared experience, despite physical differences and although Amanda noted the importance of being independent is to her, a relationship premised on interdependency is required (Hammer, 2015).

At the start of training for the marathon, Toni and Nick’s relationship did not suggest interdependency; Nick was fully reliant on Toni’s monitoring. I had asked Toni about whether he believed he was adequately addressing Nick’s physical needs by creating an adapted training programme (Abdullah et al., 2008). He admitted to not being fully cognisant of Nick’s physical needs, but focused solely on his own physical performance and whether he could successfully assist Nick to run 42km. My attention was then drawn to this possible understanding that Toni’s monitoring of Nick was for self-interest. I would often hear Toni push Nick to maintain the same pace as him throughout our 11km training run. Slowing down or walking was not an option. As training progressed, however, Toni’s various commands – “heel-toe, heel-toe, heel-toe,” “pick up your [right] foot,” “keep your shoulders straight,” “slow down” – became more attentive to Nick’s specific needs. Nick’s body no longer became the focus of Toni’s unconscious, but consciously became a site for knowledge production and a vehicle for better understanding of Nick’s ability to perform (Howe, 2011). Toni was able to push Nick beyond his own predetermined and self-imposed limitations; by actively monitoring Nick’s performance based on in-the-moment experience, he was better able to guide Nick. Nick, in turn, became more mindful of his own capabilities and became more aware of his potential in running. Toni’s commands were difficult to hear during our training sessions; however, they became worth listening to as it assisted not only Nick but also me to better engage with our bodies.

My initial interest to monitor my physical performance by utilising my Garmin watch and its heart rate monitor was ineffective. I became preoccupied with wanting to cover a certain

distance at a particular time, such that the experience of running became unenjoyable; I would neglect my bodily intuitions of exhaustion and discomfort. I felt demotivated from engaging with the recorded data of my performance, as I would question the accuracy of the heart rate monitor, and whether it was still tracking when it kept falling. Monitoring should not be premised on the effectiveness and quantity of the device, but the quality of performance and whether we are using our bodies effectively. Natalie shared how her initial use of the heart rate monitor was based on her curiosity to better understand the quantity of her performance (i.e. distance covered and level of heart exertion), but once one is more aware of one's ability to perform in accordance with their bodily capacity to endure, one becomes more interested in the quality of training. Endurance is not limited to the ability to perform at your optimal level, but rather, provides reassurance that you are able to push yourself and engaging with and respond to your own perceptions.

However, at what point does pushing oneself become problematic? Understanding the ability to listen to one's body and the body's intuition of knowing its capabilities, when are we – much like assistive technologies according to Toni – able to determine “true data” from “false data”? Are we to trust our bodily intuitions as truly reflective of our capability to perform? Or is some reliance on standards and expectations a necessity? We can only push ourselves so far.

When Push Comes to Shove

I ran about 18km under four and a half, five hours ... at about 18km my body just collapsed, from my accident my pelvis, my knees, they just said “that’s it” and I was put into the second medical tent and they said “it’s over” and I just said “’eff that,” I didn’t come here for people to say, “oh, you tried your best” and don’t get a medal ...

Bevan shared his experience of running his first NYCM in 2017 and how pushing himself too far almost became his downfall. My interview and training with Bevan allowed me to learn much about him: not only his physical challenges such as left-sided hemiplegia, pelvic discomfort or improper balance but his multiple strengths despite them. When I asked Bevan how he became a self-proclaimed “modern athlete,” he narrated his inexperience with running before his motorbike accident four years earlier. He was completely new to running and the skills that, according to Natalie, are required to become a runner. His biokineticist introduced him to running during physical rehabilitation to help him with his balance. Bevan was then introduced to Achilles International and was presented with the opportunity to run the NYCM in 2017, provided that he finished. This pushed Bevan to want to become better at running

despite various challenges that might impede the process. Initially, Bevan believed himself to be “lazy” and blamed his disinterest in running on his TBI. However, once he got out the door and went for a walk he realised the strength of his mindset, regardless of its [assumed] medical standing. Bevan’s story revealed the power of mindset to push oneself to do something seemingly unachievable. However, his experience at the second medical tent challenged his own self-determined strength. With the possibility that his marathon journey was coming to an end, Bevan decided to push himself and defy the normative standards of what it meant to be a physically active body in a social sporting event. Regardless of moments of weakness, pushing oneself can present an opportunity for self-actualisation. Realising that he was *actually* running the NYCM, he embodied his desire to become a “modern athlete.”

Toni expressed a similar sentiment when he mentioned how with the right mindset [and regimented training programme], Nick could run a marathon; he further argued that the right preparation was needed for one to successfully complete a marathon. On reflection, however, after having run the marathon with Bevan, Nick and Toni in November last year, preparation – knowing how far you can run and for how long, even with consideration for varied physical capabilities – you might never be able to adequately prepare yourself for what you, in both your physical and mental capacities, are about to endure.

Throughout the marathon, I needed the motivation to push myself as often times I spent most of my mental and physical energy pushing Bevan. From our training sessions, I had realised how easy it was to encourage and motivate Bevan, and to some extent myself when needed. I came to accept that my sole purpose as a support guide was to assist Bevan in times when he needed it most. More often than not I had to push Bevan to listen to his body and not become so caught up in the overwhelming experience of the marathon itself. This activity proved to be physically exhausting as I would often need to catch my breath after shouting for Bevan along with the spectators, it also became mentally taxing as my body became a detached re-embodiment of Bevan’s. I was shouting for Bevan, I was motivating Bevan, I was focusing on Bevan’s body that soon I became so negligent of mine. Am I pushing myself – my body, my mind, out of immediate attention? (Gabi, reflection, 3 November 2019)

You can push yourself throughout training sessions to gain a better understanding of where your potential might possibly lie; however, the true test of one’s overall physical performance lies in one’s ability to navigate the marathon experience in its entirety and extremity. Initially,

I never doubted whether Nick would be able to push himself to successfully complete the marathon because I was able to watch him progress and better himself through Toni's extrospective skills of monitoring and his ability to foster internal motivation from it. Our training sessions were still under an hour. I also never doubted Bevan's ability to finish his second NYCM, but I soon came to doubt my own. I struggled as to whether I would be able to assist another physical body so physically different from my own. At what point did my assistance to Bevan overshadow the need to assist myself? I became so preoccupied with wanting to push Bevan to successfully complete the marathon that I found it a struggle to push myself towards a mentality of any possible achievement.

My mentality thus became preoccupied with the temporary pain felt in the balls of my feet, the overwhelming feeling of being immersed by thousands of people, and the complete numbness, silence and pure loneliness of this experience. I came to question my purpose as a support guide and my own self-perception as I began to doubt my abilities to guide another individual if I found it difficult to support myself. At this point, I lost Bevan amongst the other runners. Perhaps this was a reason for the suggestion that we be physically tethered – because of the possibility that this would prevent our separation. I almost pushed myself into the nearest medical tent. I was soon reunited with Toni and Nick, who pushed me to acknowledge that pain is temporary and universal. Toni breathlessly asserted “everyone's feet hurt, and you see, everyone is still running,” and so was I. Perhaps this mental detachment from Bevan allowed me to push myself beyond the constraints of our relationship at that point. I eventually found Bevan and this complex state of endurance continued. (Gabi, reflection, 3 November 2019)

The constant still remains. As *every body* has a heart, so too *everybody* has the potential to monitor their heart; however, the measures by which we choose to monitor vary. We may wish to factually engage with heart health by actively assessing physical performance and progress against a set of predetermined datasets, or we may explore the complex reasons why our heart rate may fluctuate, even when we are exercising with little to no physical exertion. Physical performance should account for 50% of our data produced, including physiological variables such as increased breathing patterns and level of exertion placed onto the heart. The remaining 50% amounts to the richness of human experience and embodiment that cannot be represented by a series of visual graphs (Saw et al., 2016; Gabbett et al., 2017; Schneider et al., 2018). During moments of physical endurance, as much as we experience physiological changes, we

also experience moments of psychological re-embodiment of the physical body. Our heart rates might fluctuate during moments of intense anxiety when we feel we might be underperforming; however, it might also be caused by a desire to be motivated and actually engage with this experience of physical and mental endurance. This shared experience of personal engagement is what makes the phenomenon of being human all that more nuanced and complex. The inadequacy of (bio)technology to effectively consider this is what differentiates *everybody* from *every body*. Any attempt to generalise the human experience dilutes its richness.

As much as we share commonalities to the experience of *being human*, we engage in complex differences that attribute to the phenomenon to *be* human. We are not so much in the process of ‘becoming’ a particular human, through a series of engagements with our embodied sensations, as we are to ‘be’ at different stages of this exploration. In acknowledging the varied interpretations of our embodied knowledge, we are able to determine for ourselves what our bodies are capable of, not in relation to but in relationship with other bodies.

Chapter 4: Physical Self-Perception and Social Reception

“Everyone has a disability, they’re just too afraid to admit that they do” (Nick, diary entry, 27 July 2019)

Introduction

Our inability to effectively listen to our bodies by actively rendering our experiences into quantifiable data inevitably leads to our dis-ability in exploring the complexed nuances of being human. The manner by which we choose to collect, explore and value algorithmically determined data not only influences the ways in which we engage with our own bodies but also with the bodies of others. The desire to better understand ourselves overshadows the human ability to acknowledge and recognise our commonalities within others. Our attachment to (bio)technology renders the human experience unviable in physical progression and to some noticeable extent, social inclusion (Elman, 2018, Zeagler et al., 2018). Our bodies as vehicles for engagement and sites for experiential knowledge in the social [and sporting] world is rendered useless if they do not embody the quintessential essence of social ideals and sporting expectations (cf. Howe, 2011; Martschukat, 2019). At what point do these generalised ideals and standardised expectations influence the individual experiences of particular [sporting] bodies, and particularly, of individuals with disabilities? A deeper exploration of the self-perceptions of the individual and how such a self-image has been socially received, within the domain of sports participation, forms the basis for this chapter. Acknowledging the expectations of society to both create and maintain a normative standard of physical performance also requires a recognition of the seemingly unrealistic expectations of others. A greater understanding of what constitutes a “modern athlete” is needed, which recognises and affirms that anybody and every body has the potential to engage in the sensory world and explore their sense of self. Everybody also has the ability to determine their own physical perceptions and challenge the assumed normative standards of social inclusion and physical engagement (Shapiro and Martin. 2010; Scarpa and Palumbo, 2017).

“a machine is a machine is a machine is a machine right?”

Natalie previously asserted that human agency was responsible for one’s own physical performance and overall sense of physical perception. Biotechnologies have a mediating

influence on whether or not we choose to exert this level of self-determination. Biotechnologies are able to render and reduce the lived human experience into quantifiable data, and such devices too are capable of invalidating the subjective experiences of others. In consideration for predetermined algorithm datasets, the device no longer remains an external object but becomes internally realised. The device is now subjectively motivating how we engage and explore the complex human experience; along with its various interpretations by realising our physical efforts as purely numerical and factorial. The device no longer remains solely a machine, to answer Natalie's rhetorical question (cf. Rapp and Tirabeni, 2018). Natalie mentioned how her heart rate monitor and other such devices, in general, assert a degree of expectation that is required [of her] in order to better her physical performance and overall sense of physical perception. As she narrated her fitness journey from its inception during her Matric year to her aspiration to become an aerobics teacher, she further validated her use of the heart rate monitor: "If you're going to be a fitness instructor, obviously you had to be in decent condition." She saw the device as effectively aiding this process.

While assistive technologies can aid one's physical condition, they can also place one at a more advantageous physical position. I asked Amanda whether, in training for and completing the Comrades Marathon, she ever considered running without her Polar smartwatch. She replied that because there are certain rules when completing the marathon, such as making specific time cut-offs, her watch gave her an advantage: she could actively monitor her pace and determine from her performance whether she would make the cut-off in time. One's physical perception is mediated by the data collected by such devices: however, what does it mean to embody a "decent" condition and who is placed in a "disadvantageous" position? Surely, the device is intended to be marketed, as Toni professed, to "everybody...*every body*"?

When I had asked Natalie who she believed such devices were marketed towards, she replied, "different bodies with different capabilities." By 'capabilities,' I realised she was referring to one's ability to choose whether they wanted to become endurance fit or heart strong, not necessarily different in their abilities to physically perform. This ableist mentality assumes that every body has the capability to embody the same physical activities as everybody else; if you are unable to do so, such an assistive measure is not intended for you. Vanessa had accepted her new physical capacity throughout her experience of perceptual re-embodiment of a sporting self. Her preference for swimming as her chosen form of physical exercise was based on her new physical condition following knee surgery, because she could not handle the strenuous activity of running on a treadmill or "simply" partaking in local ParkRun events. Her

experience with her Garmin smartwatch, and of it not being fully cognisant of the 100 lengths she had just swum (cf. the gatekeeping metric of step counting in Elman, 2018), led to her realisation that the device could not accommodate her chosen form of exercise. She was demotivated from using it when she recognised no real benefit in it, more so than not receiving any discounts and incentives. She was in a disadvantageous position as she believed herself unable to meet the requisite level of fitness. Her physical self-perception of her new sporting self thus was invalidated by this experience. Perhaps she could have bought the more expensive device which caters for swimming, but at what cost?

I asked her to further explain who she thought were excluded by such devices. She maintained that bodies which do not “fit” the mainstream, individuals who did not actively and effectively run, are discouraged from becoming physically fit and are made to believe that to do so would be unrewarding. Such devices “take into account and recognise those that are able-bodied, anyone is differently-abled or cannot do things, you’re not recognised.” Vanessa’s disdain of such devices and intentions of their use reveals the problematic nature of prioritising one form of human experience over another. The varied complexities of human experience and what amounts to *being human* are overlooked by such assistive measures, not only devices. Vanessa continued:

The people that *can’t* get to the gym every day, who *can’t* do the steps every day, who *can’t* walk, they are *not* recognised, it’s not about that, it’s about those few able-bodied people, who are exclusive, who are people that *can* go to the gym, who can go around the block, who *can* go for a run, it’s those people who are being catered to.

What gives these technologies the potential to be assistive is not their ability to further enable those who already “can,” but to recognise the capabilities of those who “can” do, but who do so differently. Nick made a similar observation in his journal: “Everyone listens to those who are normal and see(s) to their problems before they sort out those who are different.” (18 October 2019)

This made me realise that while (bio)technology can be assistive, it only assists those who can adhere to its standard of what constitutes being *human* without taking into account the variances of this experience of *being human*. We may have come to realise the importance of listening to our own bodies, but we have yet to fully account for what it might mean to listen to those of others. (Bio)technology draws on ableist perceptions. So how are we as humans to relate to its reception?

Relativity and Relations

I asked Natalie whether she believed her heart rate monitor fully accommodates to her specific physical performance needs and if she had ever considered making use of another device. Due to her familiarity with the heart rate monitor as her only form of assistive technology throughout her fitness journey, she found her physical performance to be tailored to what the device offered, rather than to what her physical self-perceptions were and what needed improvement. Natalie has formed a relationship with her heart rate monitor that was more reliant than cognisant. Natalie claimed that this relationship and familiarity had allowed her to become confident to assist other individuals, particularly those who not only utilised the same device but were at the same “level in [her] fitness journey,” guiding them as to how they should interpret their data and better utilise it in their physical activity. Assistance was thus relative to what a particular individual was capable of achieving, and whether their chosen form of assistance could cater to their potential. I thus came to question whether Natalie believed herself to be an almost ‘personified’ form of assistive technology, not dissimilar from Toni during his marathon training with Nick. She disagreed with me: “Assistive technology in my head are about measurement and improvement, and tracking, whereas with me I’m just *guiding you* as to how to adapt of how to deal with certain things” [emphasis mine].

Her response presented the potential for a new analytical framework by which we should think not only about the assistive properties of these technologies but also guidance in general. It is not relevant that devices lack the potential to guide one’s training processes, and not especially relevant about what should be assisted and how. What is relevant is how we become better cognisant of what it actually means to assist. Natalie’s heart rate monitor guided her as to what *could* be improved, as Toni’s commands guided Nick as to what *could* be improved in his running. Such (bio)technologies become sites of guidance. How we choose to utilise them and the manner in which we listen to them is completely subject to our willingness to accept the potential to adapt. (Bio)technologies in and of themselves do not adapt to the nuanced complexities of being human. However, a reconceptualisation of “assistive technology” as a platform for such guidance and to some extent, support, is needed.

Vanessa noted that more support and guidance was needed to assist individuals in their physical performance and that this should better accommodate and recognise “differently-abled individuals.” A better understanding is needed to effectively guide one’s physical performance and support their physical progress, and to acknowledge, according to Vanessa, that

“everybody’s different and whatever you do, whatever you achieve in a day *should* be recognised, just like everyone else, no-one’s more important than anyone else.” I came to accept that there is also a complex nuance to the forms of assistance individual bodies choose to utilise and that the thought process in making this decision is premised on the desire not only for guidance but also for support. Natalie’s heart rate monitor eventually came to support her physical progress as she adapted herself and her physical perception in accordance with what she *can* improve. She realised her potential and the device supported and assisted in this growth. Nick did not make use of any form of assistive technology such as a smartwatch, and because of this, I was curious about the process of his own self-actualisation and what guided and supported him in his growth.

Unlike Natalie, Toni believed himself to be a personified assistive technology when it came to guiding and supporting Nick before and during the marathon. His self-identification was premised on his initial argument that “every body has a heart and everybody’s heart can be monitored.” He further claimed that:

No matter if you’re a paraplegic, you’re a hemiplegic, or totally physically fine, there’s always some form of exercise that allows you to increase your heart rate, and by measuring your heart rate, you can get an indication of the level of exertion you are placing your body under and therefore, an indication of how you are becoming – or what you are doing – to be more fit.

Nick, with hemiplegia, did not make any use of such a device, so how was he able to receive an indication of how he was becoming and what he was doing to become more fit? He tended to remain uncertain of his own physical self-perception. However, the decision to not utilise such technology, made in conjunction with or on behalf of Nick, was further supported by Toni’s previous assertion that Nick’s physical challenges would be inadequately reflected, insufficiently guided and poorly supported by such a device. As much as Toni believed assistive technology could better establish a training programme by recording data about one’s physical performance, he still believed that he was better equipped (than a monitor) to guide Nick by proxy to train. Further guiding his performance and supporting his progress was his knowledge of Nick’s challenges and his potential to successfully complete a marathon. Toni’s relationship and understanding with Nick led him to reflect that:

It is true that some people have physical disabilities that cause them to not be able to get to the levels of activity that [are] required in order to increase your heart rate, so it

becomes more difficult for some people to become ... yeah, it becomes quite difficult for some people to ... to create that level of activity that ... that causes their body to become fitter.

Had Nick made use of any such device, his physical performance would still be rendered unviable in physical progress, thus impinging upon any further development of physical self-perception in both bodily and social competence (cf. Shapiro and Martin, 2010; Scarpa and Palumbo, 2017). Toni's interpretation of Nick's physical performance contributed to his growth in personal competence by acknowledging and accepting his potential to complete the marathon. Nick became fitter physically and mentally while training, not because of Toni's "unbodied" monitoring of his performance, but because Toni was guiding and supporting him despite the potential for inaccuracy.

Complete and Compete

Attaining a form of competence, whether social or physical, influences one's ability to become more competent in self-assurance and self-perception. Sports participation for individuals with disabilities mediates this strive towards competence (Shapiro and Martin, 2010; Scarpa and Palumbo, 2017). In turn, assistance in forms of guidance and support from others can enable these individuals to cross the finishing line, complete the marathon, or even summit the mountain, completing the seemingly impossible (Darcy and Dowse, 2013; Hammer, 2015). However, a distinction needs to be made between one's ability to complete a self-actualised goal and one's desire to compete against assumed social and physical barriers.

I asked Amanda about her experience of running the Comrades Marathon in the past, and whether she saw "differently-abled" individuals participating alongside her. She would mention these individuals could be identified, not by their physical appearance but by the community of individuals either "tied to them" (tethered) or walking with them in a way that was unique to their capabilities. Amanda's observation thus replaces the individual's attachment to an objective device to an engagement with another subjective experience. Natalie would contend that this personal attachment to another physical body was an "abstract" relationship, implying that individuals who relied solely on the guidance of another individual were incapable of taking adequate responsibility for their own physical performance. However, what if such physical attachment is necessary to support such an individual to realise their responsibility for their own physical performance? Do these individuals remain abstract entities or do they become recognised as an actual yet varied representation of what constitutes the

capacity to endure despite imposed social and physical barriers? The challenges which these individuals experience is essentially what makes the human body amazing, according to Natalie despite her previous claim. As much as she finds wonder and amazement in her own ability to do various activities, including going to the gym early in the morning despite feeling exhausted, there is also wonder and amazement in the actions of others, despite various physical/social constraints. It is also worth acknowledging the amount of body competence required for the runners that Amanda was describing, to participate. Toni supported this claim by bringing my attention to his belief that:

... in any sporting code, that ... that – for the lack of a better word, “able-bodied people” participate in – for people that have physical challenges, the work required to, to complete the same exercise is *significantly* more ... you require significantly more work, to be able to complete the exercise, or to complete the task that the majority of ... participants in the same ... game or – in this case, the marathon – so ... human beings with physical challenges would have to work significantly harder in order to complete the marathon relevant to the *other* members completing the same race.

In order to accommodate guiding and supporting these individuals, we need to be more inclusive about what it means to embody social competence, especially in a neoliberal society, influenced by (bio)technology and influencing the standards of physical performance and self-perception.

Vanessa believed ParkRunners to be distracted by “chasing numbers” in accordance with their chosen assistive technology, and this made them lose social mindfulness of others. Their desire in numbers became a competition not only with oneself but with everyone else. I experienced this when running the marathon:

With Bevan in the middle, me to the left of him and Henry [Bevan’s second support guide in case something happens to me] to his right, we had established a sort of mental tether to each other, however, once the pacer for the three-hour finish past us, did our tether come under duress. How was I to remain out of the way and not be an obstruction to these runner’s competitive performance? Did our mental tether deter the competitive edge? After all, we are just wanting to complete the marathon.

* * *

Pacers would also run past us, giving me an indication – although false – of our pace at certain moments. I hardly made any use of my watch. I knew we couldn't possibly keep up with that pace; we were going at our own pace and we shouldn't measure ourselves against others.

The most effective means by which we can accommodate these opportunities for self-actualisation within the sporting domain is to place ourselves in relationship with these individuals. Emphasising their need and desire for better guidance and greater support despite the social and physical constraints and barriers led these individuals to believe that the incentives are not intended for them, according to Vanessa.

All humans have the desire to compete with ourselves, especially when our varied interpretations of the marathon finishing line or the mountain summit is in sight. We come to a self-actualisation based on the guidance and support of others in our potential to defy socially imposed perceptions of physical performance. We are able to realise that these constraints and barriers can be surpassed and the fact that our physical self-perception determines our ability to successfully compete against our own self-imposed and self-assumed limitations. This is so even if we can only realise our potential through the presence of others, tethered or not.

From TBI to NYC

Bevan was required to perform two tasks successfully if he were to run the marathon in 2019. Denis, the president for the South African chapter of Achilles International, had set these tasks, Denis believed the opportunity to compete in the marathon was one worth sharing with another individual, despite physical limitations. Bevan was told that firstly, he must aim to finish the marathon, and secondly, he needed to find someone who also had a TBI and help them get across the finishing line at the marathon. Bevan struggled to complete the second task as he would often tell himself:

‘You know what, I don't know if I'm gonna find a person with a brain injury to complete my task’, this was the whole two things I had to do if I was to accept this – not about running the marathon – who thinks about, ‘yeah, I'll just run a marathon!’, I thought yeah, but maybe that's just my heart saying, ‘yeah you can do it’, but then, finding somebody else and when Nick spoke to us that night about Operation Smile, I was bored – and I do get bored very quickly, and when he told us a story about, I don't know, how he couldn't, how he saw the summit and I thought, ‘flip china’ and then I cried [emotional laugh] and cried and thought, ‘who tells that story?’ it's like your

biggest moment and I couldn't believe this man standing up there telling that story, which – I know a lot of you might think, 'yeah, whatever', but not many people in the world can actually tell that story and get through to other people with such an impact, and at that moment I knew, and he didn't come into my life just because he got injured, I just knew straight away, 'this was the guy I had been waiting for', it's again like God had beamed him down here [laughs].

Bevan realised the potential in Nick, not necessarily in his ability to successfully complete the marathon, but in his ability to make Bevan realise the potential in himself. Bevan met Nick at a time when he was still recovering from his accident and when he was mentally accepting his new state of being in all of its complexity and terms of capability. Bevan's experience with his support guide for his first NYCM, in 2017, was not what he had expected. Bevan had two support guides: one who had trained with him in South Africa and was one of his biokineticists; the other he met when he arrived in New York. Angela, Bevan's wife, noted how his newly acquired support guide would push Bevan to compete with other able-bodied athletes. The guide focused on Bevan's ability to compete, without understanding the areas of performance, both physically and mentally, in which he needed support. This lack of understanding, not knowing Bevan as an individual, detracted from their desire to acknowledge the capabilities of a body that was not so much disabled as "differently-abled." Had Bevan not been pushed by this guide to be in constant competition, he may have listened to his body and avoided the second medical tent. From this experience, and having heard Nick's motivational talk, Bevan became more aware of what it meant to be a support guide, to understand the individual and to be able to recognise their potential and to respect their strengths in relation to their capabilities. As Nick's father, Toni was able to understand him and to find the advantages of how to do something differently. Toni knew that Nick still possessed the skill of running, despite his awkward gait and uneven shoulder posture.

As Toni was aware of Nick's physical capabilities and was able to contribute in Nick's growth of physical self-perception, and his ability to internalise this guidance and support, Bevan was able to realise his own potential in Nick. Nick had guided Bevan away from his negative mental state, which at the time centred on his inability to repossess his previous able-bodied identity and all of its capability (cf. Fisette, 2015), to realise that he was still capable of achieving the same goals as any other able-bodied person, albeit differently. Nick essentially became Bevan's support guide as he understood Bevan in a way that put his strengths in the forefront of consciousness. This led me to acknowledge not only the need to rethink "assistive

technologies” as including both (bio)technology but also an inter-ability relationship. One’s dis-ability thus is premised not on one’s physical challenges, but on one’s inability to understand the human body in its entirety and complexity. As Bevan saw himself reflected in Nick’s strive for goal attainment despite adversity, he was also able to better listen to his own body and gain a new-found sense of his own abilities. Bevan, by hearing Nick’s story about times when the goal is just too far out of reach, was not far enough to achieve a sense of self-accomplishment. He was able to acquire a better sense of his own capabilities and how Nick could help him reach the (metaphoric) summit. A sense of self needs recognition, and with it, there is better engagement with our sense of connectedness with one another, even if that requires using all of one’s senses.

Chapter 5: (Inter)sensory Engagement

“You see hearing tasting feeling even yes seeing with the knowledge and understanding of what is happening instead of waking up and realizing that this aint a dream” (Nick, diary entry, 13 August 2019) [unedited]

Introduction

In consideration for Hammer’s (2015) assertion that better understanding “disability” affords an opportunity to better acknowledge the richness of senses, especially in physical activity, so too one must learn to assist through guidance how to better utilise one’s senses and supportive of the multivalence of sense. Having pre-established the importance of self-perception of the physical body, and how it can be enhanced through engagement with others, in this chapter I examine the potential of our senses to further explore this new (re)embodied sense of self. Howe (2011) maintained that an impaired body acts as a stimulus for better interpreting one’s sense of being-in-the-world, and noted that sports as a sensory activity enhances a sense of connectedness between self and environment. Our senses become reactive: not only are we experienced by others through sight, sound and touch, but we become able to identify the manner in which we interpret and explore these experiences. These contribute to the complexity of *being human*. A better exploration of how our senses intervene in moments of personal struggle and act as social defiance reveal the desire to engage with the entirety of the physical body. Our senses become the immediate platform by which we experience ourselves in the social world within the domain of sports. How our bodies move through time and space reveal sites for knowledge production, influencing how we embody and engage with the physical nature of the activity. This exploration is further enhanced by the navigation of our physical selves and a sense of being, more so than becoming, a physically active body enduring a sensorial sporting activity.

“crazy eyes”

During our initial interview before our first training session, I asked Bevan not only about his experience of running the marathon in 2017 but also about moments where he struggled. I asked him if he could give me any guidance as to what I needed to do as his support guide in the 2019 marathon. He emphasised that I needed to *know* him, I needed to *want* to get to know

him beyond his physical limitations, as he would often drop “atom bombs” with his two previous guides when he felt that they didn’t really use their knowledge about Bevan when they were running. I asked him to clarify what he meant by “atom bombs.” He replied:

I have tantrums ... but the biggest thing for me – for your awareness, is to know, Angela calls it “crazy eyes,” she sees my eyes just go WOAH!” and she just goes, “crazy eyes!” and then that word normally stops me so [laughs].

It was not only about knowing Bevan in his entirety – what he is capable of and where he struggles – but also about focusing on his nuanced interpretations of his physical behaviour. I had asked him to give me an example of when he might have such a tantrum and an instance where I might have to say, “crazy eyes!” Angela replied, mentioning that Bevan could get easily frustrated, and she asked me if I were able to calm him down in certain situations, especially when things did not go his way. She continued:

At the beginning out of the starting gates, it can take a while because you’ve got thousands of people trying to move through and he just wants to start going quick, quick, just calming him down, talking him through it, make sure he understands what, why what’s happening is happening.

The total number of participants in the 2019 NYCM was 53 627, each with their own physical goals and personal limitations. The number seems unimaginable until you become engulfed by this sea of bodies on the morning of the marathon. The marathon becomes a sensory overload, especially when your self-perception as a “modern athlete” is being tested even by the regimented process of its starting procedures. The marathon officially began at 8:30 am, with wheelchair and handcycle users. Participants, regardless of physical ability, were divided into waves, numbered 1 to 4, based on the participants’ estimated time to complete the marathon. Our AwD division was in the first wave and started at 9:40 am. It was overwhelming knowing that we would be running alongside participants who intended to complete the marathon in less than three hours. It did not help that those who were AwDs, and their support guides, started the marathon beneath the Verrazanno-Narrows Bridge, whilst able-bodied athletes had theirs on the top of the bridge so that they did not interfere with each other’s physical performance. I came to realise that my assistance as a support guide came in the form of monitoring not only of Bevan’s physical performance but also of his physical and emotional responses to certain overwhelming situations. In Toni’s ideal world, a digitised assistive technology would take this into account, but until then, I would have to do.

My journey of figuring out how I could effectively assist Bevan in this instance, and others that might follow throughout our 42km marathon journey, was premised on becoming attentive to possible sensory stimuli. That winter morning was quite cold, and I worried whether this would affect Bevan's physical performance. Bevan was covered in goosebumps, his lips were quivering, and his face turned an improbable shade of purple. Once we started running across the bridge, however, the sight of discarded items of clothing ranging from temporary hand warmers to branded sporting jackets reminded me that I no longer needed to keep hold of a sponsored blanket to manage Bevan's body temperature. Our bodies started to warm up in response to the fact that we were running a marathon. Our sense of feeling cold, much like pain, was universal but it was temporary, and it no longer became a focus of my guidance measures (cf. Hockey and Allen-Collinson, 2015).

Angela had mentioned how the crowds of spectators could become overwhelming and might distract Bevan from focusing on himself. He would often engage with the spectators' shouts of encouragement and would forget to listen to his body. However, I had spoken to his previous guide with whom he had trained in South Africa for his first marathon, and she told me that as much as the crowds of spectators can be sensorially overwhelming, they could also become fundamental in motivating Bevan. Her training experience with Bevan allowed her to realise how engaged he could become not only with the crowds but also with other runners with whom he found company and support. Although it might distract one from listening to one's body, such sensorial engagement also allows for one to avoid being hyper-focused on their physical limitations. As Toni mentioned, pain is both temporary and universal. If one were to solely listen to one's body, one would make the mistake of not listening to others, especially in such a social setting. I came to realise through our ParkRun training sessions and during our half-marathon in Johannesburg that spectators could be vital in attending to Bevan's tantrums and identifying Bevan's physical response to endurance running as a shared experience. The commonality between human beings identifying and assisting in moments of struggle is rewarding, more so than receiving an incentive for listening to an external device. As Nick wrote in his journal:

Incredible stuff is happening before your eyes all you gotta do is open them up wider.
(Nick, diary entry, 18 August 2019)

From training both with and without Bevan, I became more aware of my nuanced interpretations of running and how my body responded to my interpretations. I found various

individualistic behaviours in my running that I did not share with those with whom I was running. In particular, I would often experience a runny nose. My initial reaction was to question if I was getting sick, but it became more frequent, and I learned to run with a pack of tissues. This became habitual (Bourdieu, 1980; Howe, 2011). I did not believe it to dis-able my running capacity, but I did find it challenging my endurance (Hockey and Allen-Collinson, 2015). I knew I needed to find a more durable solution to this before the marathon, as a pack of 10 pocket tissues would not last me 42km. My seemingly uncommon experience was soon challenged, when I crossed the bridge and made it into Brooklyn:

It was funny to see people with tissue boxes and paper towels. I thought when I saw the first one in Brooklyn how strange it is to have someone offering this, but when I saw so many others doing it throughout, it actually made real something I thought only I had when running, a running nose. The extent to which people were offering this was so strange to me because before the marathon I knew I would run out of tissues and would have to make an alternative plan. Unable to smell, seeing these people, hearing their offering, taking the tissue and saying thank you: people actually acknowledge that runners get runny noses and I suddenly didn't feel so different and 'unaccommodated' to anymore. Everyone gets a running nose: it is both solvable and common. (Gabi, journal entry, 3 November 2019)

It is physically demanding and mentally exhausting to run 42km. At one point or another, someone is bound to reveal their own "crazy eyes;" we just need to be better equipped to deal with this and to find various solutions, whether simply talking with other runners (as Bevan did), taking tissues (as I did) or listening to music (see below). These engagements were enriched by our senses and can enhance our sense of being-in-the-world and our self-perception. Nick shared this enthusiastically:

Started my exercises with awesome tunes in the back round, felt fresh like I could take on the world BRING IT ON BABY!! New body + new soul and new mind i dunno just feel on tops today. (Nick, diary entry, 28 July 2019) [unedited]

"jive to come alive"

At the start of my training, once I had received confirmation that I would be running as Bevan's support guide, I undertook cross-training exercises at the gym and did road running. My regime at the gym was to run on the treadmill and create a motivating and uplifting music playlist, as I found it distracting to watch the physical progress of others and listening to their breathing

patterns which inadvertently would influence my own. Listening to music would to some extent distract me from my environment and the behaviours of others, allowing me to better engage with my own breathing patterns, running pace and posture. It also helped that my chosen playlist would encourage me to run along with its upbeat pace. My heart rate monitor paid testament to that, although it did not reckon the potential of hearing on physical performance. Once I was on the road, my breathing patterns varied and I became tired, my running pace was more in line with walking, and my overall posture indicated a mix of pure exhaustion and my acceptance of underperformance. This behaviour was twofold: first, I was still in the process of becoming fit and realising my physical potential; and second, I became overwhelmed by the pure monotony of running and the solitary focus on performance, while Toni also commented on my breathing, pace or posture. I thus came to subconsciously and continuously question whether music *really* made a difference when performing. From my experience of running at the gym versus road running, the answer was self-evident; however, much like attending to a runny nose, is listening to music to better one's ability to perform a common experience?

Vanessa had emphasised her enjoyment of swimming as it gave her an hour to herself, as she was not interested in hearing the opinions of others or the behaviour nudges of her Garmin smartwatch during this time. I asked her whether her experience of swimming, much like mine with road running, ever became monotonous as it is quite a solitary sport. Her response:

I need the time for myself ... fortunately enough I have waterproof earphones that I can listen to while I am swimming and I get lost in the music and I get into the stroke, the water calms me down, *the actual habit of putting one arm in front of the other is absolutely cathartic for me*, it's like therapy. Once I'm finished, I feel as if I can accomplish whatever comes my way, I absolutely love it, I pace myself and I owe it to myself. [emphasis mine]

Music thus made the habit of physical performance and endurance personally rewarding. Vanessa's opinion of how "music makes the monotony of swimming bearable" resonated with Nick's belief that in listening to music, he embodied a new body, soul and mind. Music thus seemingly distracts from physical limitations. Nick would often journal about his struggles when performing physical activities (swimming, general cardio exercises, even our training sessions), by noting his exhaustion after a long day at work and his discomfort from his ill-adapted and generic running shoes. These factors often discouraged him from wanting to participate, but he still ran. This transition from pure exhaustion and physical discomfort to

successfully completing our training sessions and being the first one back home needed further exploration. Every day, before he swam or before we ran, he would play music, loud enough that our neighbours were also aware that he was doing so. He wrote how “doing exercises auxarily [“auxiliary”–listening to music] makes you feel alive, fresh in the morning breeze where you can jive” (Nick, diary entry, 6 August 2019) [unedited].

Vanessa, Nick and I all noted that music enhanced the experience and enjoyment of performing physical activities, although they remained just an exercise. What effect could listening to music have once it entered the social realm, wherein the monotony of performing such physical activity is mediated by the community of individuals sharing in this experience?

One of our last training sessions in Johannesburg, before leaving for New York and doing the marathon, was to walk 22km from our starting point to the Northcliff Water Tower, effectively becoming a half-marathon nobody asked for yet every body needed before we could run 42km. It was especially challenging walking the 22km. In doing this, listening to music to better your performance was replaced by exploring and listening to the bodies of others. This exercise was undertaken to test both myself and Toni’s ability to successfully guide and support Bevan and Nick respectively. Toni, at the beginning of our training journey, was unsure whether he had effectively tested his ability to both successfully complete the marathon and sufficiently guide Nick. He was also doubtful whether I could do it: his assessment of my ability to be a successful support guide was based on my inability to actively keep up in our running training sessions. It was a long walk to the Northcliff Water Tower, but we were two weeks away from the marathon and we had only one chance left to prove our ability. As I became doubtful of my own physical self-perception and perception as a support guide, I knew I was embodying this sense of doubt; however, through his confident off-key singing, Bevan supported and guided me, even if he was not aware of doing so.

Bevan thoroughly enjoys listening to music. Before our ParkRun, he would start singing and encourage others to sing along with him. Music was part of Bevan’s physical activities and part of his sporting journey; inadvertently it became quite characteristic of his performance identity (Fisette, 2015). He would sing as he ran, encouraging others to do so. He would often cite lyrics to the two songs I only ever heard him sing while he was my running partner: first, “if today was your last day” by Nickelback¹¹ and second, “some dance to remember, some dance to

¹¹ The song is called ‘If Today Was Your Last Day’ by Nickelback (2008)
<https://www.youtube.com/watch?v=lrXIIQQ8PeRs>

forget” by The Eagles.¹² His repetitive recitation of these two lines made walking towards the tower that much more bearable. I would often listen past the interpretive sentiments behind these lyrics until they resonated with my own feelings of underperformance. Interpretatively, I needed to remember why I was doing this and how important this opportunity is for myself as an able-bodied individual to assist individuals such as Bevan and Nick. They both possess abilities in need of better acknowledgement and support if any valuable progress can be made within the normalised standards of sportsmanship. Bevan’s choice of lyrics was powerful, and they pushed me to reach the top of the Tower. It was also both comedic and motivating to listen to Bevan singing along to the songs being played in each passing borough of the marathon; it felt as if we were dancing rather than running. He should consider making a poster for other runners like me.

“SMILES NOT MILES!”

One of Toni’s main concerns, when I had asked him if he had identified any foreseeable challenges for himself and Nick on the day of the marathon, was “to be able to manage the crowds and the excitement around the day, which could be quite overwhelming if you’ve never done something like this before, and then make sure we manage the pressure of ... needing or wanting to complete the race.”

This pressure was experienced not only by the athletes but also the support guides. The pressure was twofold: to cross the marathon finishing line, and to make sure that completing the marathon was still within the capacity of your running partner. This constant to-and-fro mentality was between wanting to complete the race and the need to compete against beliefs that you, as a team unit, might not be able to do so. (Bio)technology influences not only how we think about our own physical performance, but also the performance of others. This, in turn, intervenes with our perceptions of community and how support might be translated in such a social setting. The onslaught of crowds from the side can become simultaneously overwhelming and motivating; however, it was also about finding commonality in the sentiments of the spectators and how you engage with them, especially in response to the various posters which spectators shared along the marathon route.

Bevan had shared an engagement he had with a spectator’s poster in his previous marathon experience. He became fixated by a poster that read “Winner Winner Chicken Dinner.” He

¹² The song is called ‘Hotel California’ by The Eagles (1976)
<https://www.youtube.com/watch?v=EqPtz5qN7HM>

eventually asked his South African guide to take it and carry it along the route. At one point, however, Bevan questioned why she was holding onto the poster, not remembering that it had momentarily encouraged him to keep going; this was his interpretation after all. I came to question whether posters were as inspirational as Bevan suggested, or whether it was just an attractive poster and great marathon memorabilia.

When we started running the marathon, the route was quiet yet full of other runners. Once you made your way over the bridge and into Brooklyn, Bevan explained:

There's a lot of people like *woah*, there's *a lot* of people, and that's not what's wrong, you hear the storm and you think, 'what's that freaking noise?' it's like the whole city is on fire ... you won't believe it, I promise you, and at that moment, you'll know, *woah* and from then on it doesn't slow down, it gets bigger and it's – you won't believe how it works.

Bevan often experiences short-term memory loss as a result of his TBI, and he professed no detailed recollection of the 2017 NYCM. However, once we began running the marathon, in our mentally tethered positions – Bevan in the middle and Henry and I on either side of him – Bevan quickly remembered having run the marathon before. Henry ran with Bevan in the previous marathon and accepted that Bevan could not recall him doing so. The moment we entered the bridge, Bevan begins to narrate to me and Henry where the difficult moments of the bridge were and when we were about to enter Brooklyn. This re-embodiment of sensory markers based on Bevan's memories of running the marathon previously validated the richness of his senses in helping him better engage with the notion of running, and his experience of the environment enhanced this recollection (cf. Hockey and Allen-Collinson, 2015).

* * *

The experience really is unbelievable. You become overwhelmed by the enormity of the crowds that are present throughout the entire marathon route. I initially felt such an experience to be overwhelming; however, knowing how much Bevan gains from this kind of attachment to others, I interpreted his behaviours and actions as inspiring and motivating, to the point where I asked him which poster he liked and whether I could carry one for him. I became better engaged with the crowds of spectators, in how they shouted Bevan's name – his name was written across his running shirt, how they openly offered boxes of tissues, handing out bottles of water and slices of oranges. They even played 'Hotel California' (1976) by The Eagles. The crowd provided the kind of assistance, guidance and support that Bevan needed and in

hindsight, so did I. I came to embody their sense of connection to the runners and especially, the sentiments they shared through the medium of posters. I was able to identify five different styles of posters throughout all five boroughs: first, interactive (“TAP HERE FOR ENERGY!”), comedic (“SMILE IF YOU PEED A LITTLE”), personal [often encouraging particular runners], food-inspired (“KEEP GOING! THERE’S PIZZA and/or BEER WAITING FOR YOU AT THE FINISH!”) and motivational (“YOU’RE ALMOST THERE!”) – the latter even when we had only just entered Brooklyn. The poster which encompassed three of these styles and carried me through the next two boroughs and their physical and mental challenges was “SMILES NOT MILES!.” It was firstly interactive: seeing it and watching the person holding it smiling and telling you to do the same instantly made you embody that feeling. Secondly, it was comedic, for at this point in the race it was more about miles than it was smiles. Thirdly, it was motivational: it made me realise I should not focus on the racers passing us but rather, enjoy this experience and be in-the-moment with Bevan. I had previously experienced this triad of complex engagement when Bevan would sing as we ran in our training sessions. I realised just how powerful words on a piece of paper could be on one’s physical performance and a sense of self. At that point, I knew that if the posters carried on through into Manhattan and over that “LAST DAMN BRIDGE!” we would be able to complete the marathon, with both of us able to compete against self-imposed mental blocks, which Toni believed could be avoided by adhering to the “facts.” We were about to go over the “last damn bridge,” and if it were not for that individual reminding to push ourselves, we would have remained on that bridge. We were able to embody these sentiments, and through our ability to continue, to show our appreciation of their guidance, support and assistance.

Excellence Through Communication and Everything You Need Out There Is in Here

As we made our slow ascent up the hill and towards the Tower, I focused on getting Bevan to the top more so than on my own capability to join him. Suddenly, he stopped, calls Nick to stand next to him, takes out his cell phone, and begins to take a number of selfies. Denis later joined our walk and told Bevan not to stop and to “keep moving those arms!” Bevan continued to take selfies and eventually told Denis, mid-moment-capturing, that “it’s about the journey and not the destination.” Bevan could have taken the photo with Nick once they had reached the Tower, but Bevan found it more fitting to capture the moment of near “summiting” and to always be reminded of how he assisted Nick in reaching his next “summit.” A picture – a poster or a selfie – really does say a thousand words. I knew that both of them were able to get

to the “summit,” or simply, the top of the hill. It was just better captured by these selfies than could ever be recorded by an assistive (bio)technological device.

* * *

One’s ability to effectively and actively engage with one’s senses enriches not only the sporting experience but the essence of what it means to *be human*, with sensorial engagement further contributing to our general sense of being-in-the-world. Our sense of self is enhanced when our behaviours are reflected through our bodies in motion. As humans, we are able to guide the experience of others in a direction that supports their potential and assist them to realise their goals. Our capabilities lie in determining overwhelming situations based on the look in our running partner’s eyes, accepting the offer of tissues, or enhancing the communal shared running experience by listening to a variety of music preferences or the relentless repetition of specific lyrics. It could even be through the ritualistic practise of preparing and sharing, and the sense of togetherness, created by food. Enjoying the taste and savouring the distinct smell of various pasta dishes enriches this sense of community created around it, consumed and embodied (Mol, 2002; Lupton, 2016). Two nights before the marathon, Achilles International organised a dinner at which all AwD, their support guides and other supporters, such as family members, shared in this experience. A sense of community was created through this shared human practice; food not only became a form of assistance in our training but also allowed us to engage and better understand others, as individuals rather than as AwD.

At one point in my training with Toni and Nick, Toni would only consult with his Garmin smartwatch when we reached our final destination, to see whether he had reached his specified numerical goal for the day by seeing his total step count. The distraction of instructive criticism was absent at this point, and our ability to connect with our holistic sense of running was put clearer into consciousness. I was slowly starting to enjoy the feeling of running again, even without music. With both Toni and Nick running in front of me, I was in a better position to observe their performance and relationship. Once I was confident with my breathing patterns, running pace and posture, I was drawn to Toni’s and Nick’s running shirts: Toni’s read “excellence through communication” and Nick’s “everything you need out there, is in here.” I had seen them wear these shirts before but had paid no attention to them as I was more focused on whether I was effectively communicating with my body and if I would be able to finish the whole 11km. The sentiments of their running shirts reveal the ability to find our potential in ourselves through our engagement with others. My engagement with these words allowed me

to look past how guidance was being offered and received, and instead focus on how this navigation of self in relationship with others is better enhanced as a holistically supportive measure.

Support is a nuanced complexity as part of the human experience. Better acknowledgement for how our senses mediate our experience of running and exploring self and others is needed to better understand notions of support. We need to better understand how support transcends beyond simple guidance and assistance and moves to a sense of connection and togetherness that cannot be defined by our tethered attachment to (bio)technology, one which disconnects what it means to *be human* from the *human being*.

Chapter 6: Support Systems and Modes of Support

Gabi: Do you think when you're running the marathon and people see you with a support guide – do you think having a support guide takes away...

Bevan: ...uh uh, I don't want to be funny now, but I think it highlights the fact that there's a guy here that needs support, but actually, when you talk to him, maybe he doesn't need support, maybe he just needs a person there – which is support hey?
[laughs]

Introduction

Supporting a person's journey for greater cognisance of embodied knowledge, realising their physical self-potential and embracing the richness of engaging with senses in their entirety, offers better insight into the complexity of human experience and human connection. This arguably cannot be satisfied by a physical and social tether to an objective device. To support a human being encompasses the richness of subjectivity and sense of togetherness that can be created in moments when we allow such personal attachment. Hammer (2015) considers the importance of being in bodily presence with another individual, and this allows for both the proxemic connection through space and time and the personal engagement needed to better enrich this shared experience. Bi and colleagues (2019) maintained that establishing a personal connection with other physical bodies, such as spectators and supporters, allows endurance through adversity – cognitive, psychological or emotional, and to some extent, social. The incentive behind utilising assistive technologies such as digital wearables is influenced and motivated by the need to constantly better one's physical performance, and through increasing goal requirements, this subconsciously promotes the idea that one's true physical performance can never really be met. If one were to remove the device and instead offer support based on one's ability to defy social standards of physical performance, a true representation of one's physical self can be actualised. In this chapter, I explore what it means to support a sporting body, without focusing on physical limitations and challenges. Through observational accounts, participatory shared experiences and post-marathon reflection, I was better equipped to understand and acknowledge the nuanced complexity of support; it varied in form, ranging from water [both in swimming and when offered by hydration stations] to fortified running

shoes, seeing your family and friends along the route, to simply knowing your running partner's name.

The Guidance Continuum and the Problematic Binary

Achilles International hosts an annual dinner for all AwD runners, usually on the Friday before the marathon. At this dinner, you come to realise the extent to which support is utilised and how it varies – a modified prosthesis, mechanised wheelchairs, and the simple embodiment and personification of support guides. I was amazed not only to witness this sense of community, enriched by this shared experience of enjoying food but also, to realise that in this engagement, physical differences do not come into immediate consciousness. Every body is accommodated by carefully thought out accessibility points, acceptance of various assistance measures, including guide dogs or the simple physical tether between a vision-impaired individual and their sighted support guide. The personal connection and relationship of support are not simply unilateral between an able-body and a body with a disability. This enriched my understanding of what it means to support another human.

As we entered the Hotel Pennsylvania where the dinners are annually held, we immediately became overwhelmed not by the sheer number of AwDs running on behalf of Achilles International, but by the various modes of support they utilised, even to make their way towards the elevator and into the ballroom. Toni, Nick, my mother and I made our way into the elevator and as the doors were about to close, we were asked to hold them open. As we did, a vision-impaired individual – identifiable by her white cane – entered, her arm interlinked with another person who also had a white cane and was partially vision-impaired. They were tethered and were a unit of support and access into the communal dining space. As the ballroom was on the 20th floor, we had time to engage briefly with these two individuals. The partially-sighted man was from New York; his tethered female friend was from New Jersey. As the man had previously run marathons for the organisation, he had developed memory markers of how to get from the ground floor of the hotel to the ballroom; he needed assistance only to call an elevator, as we did (cf. Hockey and Allen-Collinson, 2015). As we ascended, I reflected on how being a support guide was not premised on being able to assess Bevan's physical performance and not even the need to be able-bodied. Support is non-binary and exists along a continuum, varying from a white cane to the simple attachment to another individual familiar with your experience of being and able to navigate around its complexities. Support thus

revealed itself as a mechanism of interdependency, defined not by one's ability to endure but by one's ability to enable the possibilities for and with another individual.

Upon entering the ballroom, we said our goodbyes, and I felt it almost condescending to ask whether they needed further assistance at that point; rather we supported them in their ability to figure it out for themselves. Their vision was impaired, but both were able to utilise their other senses in navigation with confidence and trust in one another (Hammer, 2015). My marathon journey up until this point was unaware of how Bevan was supporting me in my physical performance and personal self-perception. I often felt incapable of adequately assisting, guiding and supporting Bevan in his progress and potential, and I had overlooked his assistance, guidance and support of me. Before our training sessions began, I would often find myself researching how to be a support guide so to assist Bevan. Surprisingly enough, there is information on how one should run the marathon, from where the route gradually inclines, to moments where one can catch their breath. There was, however, hardly any information that could assist a support guide to assist another individual. It was a matter of figuring that out for myself. I paid most attention to areas where Bevan struggled and tried to adequately accommodate them, but I was unsure how to do so especially because running 42km requires some personal assistance for myself as well. Having met the two individuals in the elevator, I came to understand that the process was not so much about gathering as much information as possible about your running partner, but about learning about each other and learning to run together.

Forming and maintaining relationships is part of being human: we are social beings. I came to realise through my engagements with Bevan not only the importance of companionship but also its necessity in a sporting and supporting context. As much as companionship is subjective, it can also be objectified.

Lupton (2014; 2016; 2017) and Mol (2002) maintain that companionship with a digital device is worth acknowledging but also criticising. Both authors suggest that the users of these wearable biotechnologies consider the influence of data analysing on the subjective embodied knowledge of the sensorial body. Toner (2018) maintained that as much as users might feel “naked” when they are not wearing their smartwatches – especially after forming a companionship with them – this feeling of vulnerability and exposure is not an inherently negative experience. Toner (2018) suggests that users listen to their bodies, and not allow their

physical experiences to be mediated by an objective “unbodied” device (Ruckenstein and Schüll, 2017; Smith and Vonthethoff, 2017).

On Sunday 15 September, our team ran our first half-marathon (21km). Normally, in order to qualify for running the NYCM, one needs to have completed either a half-marathon or full marathon within a certain time, relative to age and gender. The entries of individuals with [physical] disabilities are entered into a draw and participation depends on the outcome, which in both Bevan and Nick’s case, was successful. Our intention of running the half-marathon was not for guaranteed entry in the NYCM, but personal curiosity. This was quite different from our usual 11km weekly training sessions. In these sessions, I observed how Toni would constantly monitor both his and Nick’s progress through his Garmin smartwatch. I was quite perplexed initially, as I did not understand how Toni could monitor *another* physical body through a device that was intended to monitor only his. I struggled with his intentions; however, the results at the end of the session were clear. Both Toni and Nick finished in good time, doing one kilometre in less than eight minutes although Nick still struggled with his right-side gait, enough to need a modified pair of running shoes which he also used for the NYCM. I decided to use this Sunday morning to monitor both Bevan’s and my progress by tracking our time on my Garmin smartwatch. For perhaps the first eight kilometres, my constant and exaggerated arm movements, from helping me propel my body to helping me read the time, led me to believe that we too were making good time. I could see Bevan’s curiosity and his irritability. He would constantly tell me to stop looking at the time and be in-the-moment. I intended to make it across the finishing line with Bevan with time to spare; his intention was to simply enjoy the experience. His comments, and my physical exhaustion from this arm movement, soon proved too much; at the time I did not even know when and if I would finish the half-marathon. In the end, we learned much more about each other and ourselves that was otherwise absent from constantly assessing the time. I learned that Bevan struggles with his asthma when he tackles hills; I learned that Bevan’s nose constantly runs when he is running – just like me; I also learned that Bevan’s left side, and particularly his pelvis, really hurts after running for some time. Had I not paid attention to these embodied sensations, I would have not been able to give Bevan his asthma pump when his breathing became shallow; I would not have passed him a tissue, or suggest we stop and walk for a bit. We would not have finished.

Bi and colleagues (2019), based on their study of able-bodied athletes and supporters, reiterate the importance of constant support, assistance and motivation throughout a marathon, and the desire both to receive and give necessary and individualised support during a marathon. Long

Distance Racing Events (LDRE) encourage spectators and supporters to utilise smart technology – visually following athletes through the use of drones, watching the event on television, or even making use of mobile apps to constantly monitor and alert spectators about their runner’s every move. However, spectators/supporters feel even more distanced and consider themselves “passive” in their SRI team identity (Bi et al., 2019). Runners expressed the same attitude. Instead of being followed by drones and cameras and monitored by smart devices, they wanted to know that their spectators/supporters were emotionally and cognitively supporting and motivating them, especially when they made brief contact with each other during the event. As impractical as it is to suggest for these spectators/supporters to be with their runners throughout the event, being a support guide provided me with a binary position wherein I found a middle ground: as Bevan’s running partner and as Bevan’s supporter, assisting his emotional, cognitive and physical needs. A device might be able to assist in one aspect of overall performance, but it does not support the nuances of our lived experience as social beings. As much as my attempt at time management failed to enrich my experience of running, it did allow me to realise the importance of being-in-the-moment (Merleau-Ponty, 1962; Howe, 2011). Completing the half-marathon with only 10 minutes to spare – as per my emailed race results – made me realise that my companionship with Bevan could not be measured by time, distance covered, or active heart rate, but rather by our experience of the event and our engagement with each other. We even have a medal to show for it.

Family and Familiarity

I developed a familiarity with how Bevan engaged in his environment, while slowly realising his influence in supporting me in my physical progress and perception as his support guide. This familiarity, like Natalie’s relationship with her heart rate monitor, became my first and only real experience of how I should engage with this journey of becoming not necessarily physically fitter, but rather, better equipped to support Bevan, and to some extent myself. I had developed a relationship with Bevan. As he noted in our interview after I asked him about his current progress and what was assisting him to realise his ability to finish the marathon for the second time,

I’ve had many dreams about us as a team [myself, Toni and Nick] going through there, and that’s not like [emotional] it’s not the destination, it’s the journey, that whole marathon is the journey – *this* is the journey, so, for me to do this, for us to get as a team, through [as] one, it’s gonna be amazing, that’s the only dream I have right now.

As much as it is about mindset and being able to foresee oneself already at the finishing line, it is also about being able to create and maintain a relationship with a support system to get there. Bevan had always mentioned that he felt part of my family as much as he felt about being in a team with me, Toni and Nick. We developed such a close relationship with one another that it was no longer about Toni being Nick's support guide and me Bevan's; it was about this need to personally support and guide one another, as a family does, in reaching a particular goal – crossing the finishing line or reaching the summit, metaphorically at least. You come to form a supportive attachment to one another, and this is often realised in physical proximity when running, or mentally, in our ability to acknowledge our struggles and see the strength within them (Hammer, 2015). I asked Nick if he found it at times frustrating when Toni would tell him to pick up his right foot, run heel-toe and not toe-heel, or slow down his pace. He replied that it did not, because he came to understand that while Toni could not experience his struggle with hemiplegia, foot positioning or his discomfort when running at a slower pace, he understood where Toni was coming from and Toni's ability to see the potential in Nick, even after the accident. This particular response is best noted in Nick's journal, in which he writes:

Having one of those dudes you get in the ARMY saying 'left right left right' and singing a song while still doing high knees. You see I need that person by my side as I accomplish the marathon *luckily my DAD is my guide who will do that Any given Sunday*. We sweat and bleed for those inches (Nick, diary entry, 6 October 2019) [emphasis mine]

Darcy and Dowse (2013) noted the importance of family members participating in sporting events, particularly in the case of parents of individuals with disabilities. Not only is the parent able to realise the potential in their child to perform with other athletes, but is also able to foster a more cohesive relationship and sense of family well-being. There is enjoyment when sports participation is shared, especially with those who already have a pre-established personal connection, to help the individual grow and to grow from this experience themselves. I went on to ask whether Nick believed he would still need a support guide, given his training with Toni before the marathon and his improved physical performance, based on Toni's monitoring skills. He responded that he would still need him: "Everyone needs help and I do think I need someone to get me back on my feet, to get me back to where I need to be, like, if I slow down or I don't want to do it anymore, he's always there to encourage me." I came to realise the sentiment in his desire for continuous support when he wrote in his journal: "being a dad is not

an easy task but when it happens your talents come alive. Be that torch that your kidz wanna see and shine for them.” (Nick, diary entry, 27 October 2019) [unedited]

This also resonated when Toni struggled with asthma as a result of hay fever when we trained in winter, and his unrelenting determination to keep running and not turn around and go back home. Toni became simultaneously Nick’s guide and supporter during his marathon journey, enriching a sense of human connection throughout. As much as it would have been beneficial to listen to his body during those times, Toni taught both Nick and me the power of mindset. Nick and I became Toni’s supporters, encouraging him to not give up, when in hindsight, that was probably [medically] problematic. All that matters, again according to Nick in his journal, is not our assumed inability to finish, but “the only people we need to worry about is those who have been with us for the long haul.” (Nick, diary entry, 25 October 2019)

Amanda had mentioned how for the first five years of her husband running the Comrades Marathon, she was always his supporter, encouraging him along the route, until eventually, based on his experience of Amanda’s growth in physical performance and self-perception, he encouraged her to join. Her ability to participate in this ultramarathon was not so much influenced by her engagement with her running community as having the right mindset to perform and her husband’s ability to identify it. This kind of relationship follows from Allen-Collinson and colleagues’ (2018) assertion that endurance, whether physical or mental, is not so much about mind *over* matter as the relationship between mind *and* matter, and the ability to push oneself towards a sense of achievement, even if this is realised through the experiences of and our engagements with someone or something else.

Mind and Matter

After a motorbike accident, Mark re-embodied a new sense of self that was now limited in its functionality from his triceps down. On the morning of the marathon, he needed further assistance despite having a modified handcycle to compete in the marathon. Toni and another support guide, Hein, made sure that Mark’s feet were comfortably strapped to his pedals and his arms securely Velcro-ed to his handles as he cannot grip them. He did, however, ask me to help him programme his smartwatch to monitor his GPS coordinates, distance covered and active heart rate. I did not find this as strange of a request as I thought I would. From the moment I walked into the AwD tent, I was overwhelmed by both the number of athletes and their various “different abilities”. Perhaps not to the same extent as able-bodied participants, there was also curiosity among AwD to monitor their performance in relation to their physical

selves, bringing into reality through recorded data a record of their endurance despite social ideal and imposed sporting constraints. Before his accident, Mark had been a competitive sporting body and monitoring such data fitted his performance identity, or rather my idea of it. Asking me to assist him now supported his perceptions of self, that despite his physical limitations, he was able to re-embody a sporting body, even if differently. I felt proud to be part of this assistance and grateful to have been part of his support system during his three-hour marathon experience.

I had asked Vanessa what she considered to be her greatest form of support when swimming, considering her dislike for another person to guide her own physical performance, and notwithstanding the assistive features of listening to music to counter the monotony of swimming. Her response was simply, water. Water and the ability to experience her body as it moved through it became more assistive and better in guiding her physical self-perception as her physical body performed best and was better accommodated by the weightless sensation of aquatic exercise. How she thought about her capabilities and its translation into re-embodiment was supported by her ability to navigate through water, and to take advantage of its calming effects. It supported her journey of self-rediscovery and assured her of her potential to redefine what it meant to be a physical self; this mentality mattered in her growth. Having already identified the multivalent capabilities of different individuals who are able to do the same physical activities although differently, utilise different supportive measure in doing so. Vanessa and Mark both still believed that they exerted the same level of physical performance in physical activity, although this was adjusted to their (new) physical capacity.

The day after completing his first and only half-marathon, in qualifying time, Nick went to go see a podiatrist, putting our team training on hold for the rest of the week. It was probably during the last eight kilometres where you could see that Nick was really struggling with his right foot, having to actively lift it to avoid it dragging on the road. Physically, he was struggling; verbally, he was expressing it. Throughout the run, we had told him to slow down as he liked to run ahead. I knew from experience that he tires quickly, and this takes a physical toll on his impaired body. Toni told him to slow down and focus on his breathing, however, this conflicted with Bevan's persistent conversation, continually stating how proud he was of Nick and himself. As much as Bevan helped distract Nick from the pain of his foot and his irritation, he needed more assistance from Toni, telling him to conserve his energy and focus on his breathing and "remember, heel-toe, heel-toe, heel-toe" (cf. Leder, 1990). Bevan's distraction contributed to Nick not focusing on his body and having to visit the medical tent

immediately after completing the run. Nick “toe-heeled” all the way to his diagnosis: he needed modified running shoes, adapted to the structural support needs of his right foot and physical body. I believe that as much as Nick needed Bevan’s emotional support, this was not sufficient to counter his physical discomfort. Similarly, Toni’s objective instructional support of Nick discounted Nick’s actual subjective experience. Bevan and Toni were the Yin and Yang support systems for Nick, the ebb and flow of his progress and final outcome. This experience, and my analysis of it as both a researcher and support guide, helped me to realise that support and assistance are multivalent, and could be in the form of a human being or even a pair of running shoes. Perhaps, as much as a (bio)technology disengages with the human experience, so too do people: some focus on the emotional response (cf. Bi et al., 2019) and others on physical performance (cf. Abdullah et al., 2008). It was, however, a learning process; Toni needed to acknowledge Nick’s emotional subjectivity and Bevan needed to understand that the marathon was just as much about Nick finishing as it was about him doing so.

I asked Toni what he believed was required to successfully run a marathon from his experience of training with Nick. He listed: “You must have the right clothes, you must definitely have the right shoes, the right mindset, a good training programme ... and *some* assistive technology would help.”

I did not necessarily believe this; my initial analysis of Toni was one attached to such (bio)technology to perform to one another’s physical potential. This changed however when I saw his actions when he assisted Nick to put on his foot brace and modified shoe in-sole, as per doctor’s instructions; and even more so in the marathon when the only time he looked at his Garmin smartwatch was later that night when he asked me to guess how many steps he had taken. It took a total of 64 350 steps – compared to the standardised 10 000 steps a day – to realise the importance of establishing a disconnection between “facts” and performance, and rather become better tethered to maintaining a connection between “feeling” and human experience. Nick’s modified running shoes assisted in his physical performance, but feelings of pride guided Toni into realising the importance of sharing this moment of astonishment. Nick’s physical vulnerability and Toni’s emotional and to some extent social vulnerability revealed the interdependent nature of support; Nick’s ability to push his physical boundaries was reciprocated by Toni’s effective guidance towards the finish. Nick’s shoes helped him run those same number of steps as Toni. Toni was able to support him in every one of those steps. Toni had believed support should be mediated by actively monitoring one’s physical performance by assistive technology, but he came to realise that support is multivalent and

much like the shoes, one size does not fit all. What mattered was to recognise Nick's strengths despite his physical limitations. Knowing Toni's difficulty in expressing his emotions verbally and on paper, words became irrelevant when I saw his simultaneous smile of joy and tears of pride when Nick crossed the finishing line. As part of being human, we face moments of difficulty. With the right mindset, support system and shoes, in this struggle, we find commonality, connection and a sense of togetherness. Toni perhaps never realised how a pair of shoes could better assist Nick's performance, in contrast to his Garmin's ineffective ability to do so. I have yet to see Toni remain as tethered to his device as he was when we began, and especially after he crossed the marathon finishing line, hand in hand with Nick.

Together

Denis constantly suggested that Bevan and I be tethered to each other when we ran the marathon. We were encouraged to consider that because the day would be overwhelming and because of the sheer number of runners, we would lose each other – which did happen. Every time the suggestion was brought into the conversation, I asked Bevan for his opinion about being physically tethered, utilising the same tethering technology as a vision-impaired runner with their support guide. Understanding that my job was to not lose sight of or grips with him, Bevan reassured me that:

Your job is not – in my mind, not a physical job, it's a mental job, that's what I think because, if my physical part breaks down, you can't carry me, you've just got to get my mind right, say, 'come, get up!' or 'do you *really* want this?' and people telling you, 'you've tried your best but couldn't make it' – you've just got to find ways to just drive that – but we're going – there's going to be four of us so actually, we're all going to be guides for each other.

Thus, rejecting Denis' decision. In Bevan's opinion, it would be impractical to physical tether a guide to their running partner. I came to understand my role as a support guide a lot better. It was not about physically pushing Bevan, but about creating and maintaining a connection with him, and this could not be realised with a tether. Bevan maintained that without a support guide for both his 2017 and 2019 marathons, he would have struggled to finish. I questioned this because he has the physical ability to complete the marathon, but I realised he just wanted to feel a connection and sense of togetherness in his experience, and to be able to share this with somebody who understood him. I realised the importance of such a human interaction

especially after he shared an experience with his unfamiliar guide in 2017. He claims that the only memory he has from the marathon was:

When we were putting our numbers on because on my shirt it says, whatever and on your shirt it says – and we run in the Achilles shirts, you will see them, it says, ‘Guide’ and that lady is a runner, and she put her number over the ‘Guide’, cross it off, and I saw this and I thought, ‘why?’” because to be a Guide I think must be a proud moment, like what more moment would you do that? ... and *that* disturbed me a lot, that, why would she use me? Or this for her own purposes? ... and for that reason, I got very upset with her, and I think that tired me down a lot in the run.

Denis’ constant insistence that Bevan and I be physically tethered was problematic. Not only would this proxemic attachment impinge on our natural running styles, but it would also undermine our independence and agency (Hammer, 2015). I knew that by drawing more attention to Bevan’s physical limitations through (bio)technology would influence his physical self-perception (Zeagler et al., 2018), in a similar way to his previous guide’s wish to make invisible her connection to Bevan. Bevan did not need to be physically tethered to succeed; he needed to feel a sense of togetherness between runner and guide, a shared mentality for success and human connection. I rejected Denis’s advice based on my acknowledgement of Bevan’s previous experience. I came to recognise another instance in which a physical tether could have been effective in assisting my mentality, but was problematic as it would not support Bevan’s physical capacity.

I managed to run just under half the marathon with Bevan and Henry but was eventually unable to physically keep up with their pace. Because Henry had experience in running the marathon, he was more instructive in how Bevan should perform at certain points along the route; as I was inexperienced, I simply followed Henry’s instructions and only intervened when I thought Bevan could use his asthma pump or have a sip of water. Henry embodied the support guide I knew I needed to be for Bevan; unfortunately, I could not live up to his expectations. I felt guilty for not being who Bevan needed me to be, given the relationship we had established. I also felt a sense of burden upon completing the marathon and feeling my medal being placed around my neck; who was I supporting, when I had crossed the finish line alone? Perhaps it was in my own self-interest to live up to what my shirt said, about crossing the finishing line with my running partner. But had I been tethered to Bevan, I would have undermined his ability to finish in accordance with his physical capability. This was evident even in our training:

Bevan and even Nick would always be in front me and I would often feel embarrassed at finishing after someone with a physical disability when I did not experience such physical constraints. On finishing the NYCM, however, I was not embarrassed: I was proud that Bevan had finished at a time better than his previous marathon, which was one of his goals. I was also thankful for Henry in helping Bevan get there – I would have held him back. I was proud to still show my ‘Guide’ above my race number, and I effectively guided myself across the finishing line.

At the Achilles International dinner, awards were presented, ranging from the global chapter which had most increased its number of members – which was Mongolia, to aspiring young AwD who showed the unrelenting human spirit to never give up. There was also an award for the most inspiring support guide, and the recipient of the award mentioned in their speech that the role of any support guide is to support and guide anybody and *every body*, even if you were the body in need of both. My guidance including reassuring myself that Bevan could cross the finish line, which he did 4 minutes and 43 seconds before I did, and that I needed to support those around me even though I was struggling with my own physical performance. I was particularly drawn to one of Nick’s responses to my questions about the need for support guides. He replied: “Guidance, you always need a guiding light, a guiding light to look upon for inspiration.” It was quite fitting that our Achilles running shirts were bright yellow, especially good for reflection when running on the road, for identifying members of the organisation’s running community and metaphorically, for spectators’ ease of observation. With only five kilometres to go until we reached the finishing line, I found Toni and Nick. I identified them by their shirts, but I could also hear the spectators shouting out Nick’s name and encouraging him to keep ongoing. AwDs commonly write their name on the front of their shirt so that when they run, spectators are able to encourage them and support them. I ran the remainder of the marathon with both Nick and Toni. I was motivated by Nick’s unrelenting ability to push himself and Toni encouraging Nick every step of the way. I was discouraged that I had separated from Bevan, but after the marathon, I reflected:

I am here to help individuals like Nick and Bevan. Toni was emotionally invested in Nick’s name being shouted and feeling proud of his son; I too should be proud of my brother. I am *able* to complete this marathon without a leg brace. Nick at this point in the marathon needs to be reminded that his leg brace does not define him nor distract others from the fact that he is a person named ‘Nick’, not a disability. (Gabi, reflection, 3 November 2019)

While I was a support guide, I am firstly a human. Anybody and *every body* needs support and guidance, no matter their physical and mental ability. We are all impaired in one way or another, we need to accept this, and accept and appreciate the support and guidance of others. I came to realise that my biggest support lay in my weakness, and how I was able to recognise the potential in myself to push myself with the help of my engagements with others. I remember watching Nick and Toni crossing the finishing line and thinking how fortunate I was to experience something like this with my brother and my father, not as an individual who used to monitor their and their running partner's physical performance against a predetermined data set or in the context of an individual who is physically disabled. We had finally reached our "summit" with a smile on our faces and gold medals to show for it.

The day after the marathon, participants walked around the city with their medals around their necks. People congratulated each other and shared their experiences of running. A sense of community was established by the medals. You were able to recognise the endurance it took to complete the marathon. Anybody and every body who had completed the marathon shared the sentiment of connection and togetherness. No-one asked about Bevan's or Nick's disability. They endured the same physical activity and exercised the same degree of agency to perform (Maralack, 2016). The physically disabled body and its assumed and superimposed limitations and inabilities did not come into active discussion. It was absent from one's mind, especially when a big gold medal and showing it off was distracting you. This is all that really mattered.

Chapter 7: The Finish

With the literature presented, greater acknowledgement and better understandings are needed to appreciate the value of human connection, particularly within the sporting domain, for individuals with – and without – physical disabilities (Hammer, 2015; Bi et al., 2019). Howe (2011) maintained that there needed to be a re-evaluation for how we engage with our physical selves in physically demanding activities, and noted how our subjective bodies, multivalent experiences and environmental engagements shape the ways in which we formulate and situate our sense of being-in-the-world. Toner (2018) and Rapp and Tirabeni (2018) support this argument, while also suggesting that utilising assistive technologies such as digital wearables (Fitbit in Elman, 2018 and heart rate monitors in Saw et al., 2016; Gabbett et al., 2017; Schneider et al., 2018) detract us from engaging with our physical bodies during physical performances, by instead focusing our attention on a series of numerical inputs and outputs (Lupton, 2014; 2016; 2017; Ruckstein and Schüll, 2017; Smith and Vontethoff, 2017). While technological advancements may help offer individuals better understanding of aspects of their physical selves, particularly total step count and average heart rate, they do not enable a better understanding of the physical body as a holistic entity (Saw et al., 2016; Gabbett et al., 2017). In addition, we need to better understand and acknowledge the cognitive and emotional (Shapiro and Martin, 2010; Scarpa and Palumbo, 2017; Bi et al., 2019), environmental factors (Howe, 2011; Hammer, 2015; Hockey and Allen-Collinson, 2015; Allen-Collinson et al., 2018) and support systems (Bi et al., 2019; Darcy and Dowes, 2013; Darcy et al., 2017) that contribute to the lived experiences of sporting bodies. These notions oppose the neoliberal agenda of compulsory ableism and socialised mentality surrounding health and fitness. Hammer (2015) and Fisette (2015) argue that individuals with physical disabilities should not be reduced to their assumed inability to actively perform in a manner that adheres to a kind of “law of averages,” as Toni describes it. Rather, we should further enable and support their engagements with themselves, their environment and others to be realised and accepted as a new alternative experience for such forms of performance. In this research report, I have given particular attention to these alternative forms of human experience within the sporting domain, and have shown how human beings are perpetually in a state of redefining what it means to be human and reimagining personal achievement, a sense of community, and belonging that is inclusive

of every body and does not reduce experience and engagement as generalisable and concurrently tied to ablest norms.

Through active discussion with my participants, decisions surrounding what forms of “assistive” measures might be utilised, if any, in their physical performance and throughout their sporting journey derived from what they wanted to achieve for themselves. My able-bodied participants wanted constant monitoring as a means of self-assurance, knowing through actively tracking their physical activity that they were embodying what constitutes being fit and healthy (cf. Martschukat, 2019). Heart rate monitors and smartwatches served this purpose. My “differently-abled” participants, however, revealed through their narratives and actions the inadequacy of such devices to accommodate their experience and engagement, during training and in successfully completing the 2019 New York City Marathon. For such individuals, self-assurance was also needed, but this was not to be provided to them via an objectified device (Smith and Vonthethoff, 2017). In conversation with both my running partner and my brother, in running, their own engagement of their physical selves, their immediate environment and support systems all re-assured them of their ability to actively participate in a communal activity, despite doing so at a different pace. There is value in removing the problematic tether to technology that we have established for ourselves; our attachment to render human experience into quantifiable data sets removes the complex nuances that make us human beings and are the basis for human connection and sense of togetherness (Hammer, 2015). The motion of physical performance and the notion of being-in-the-world are synonymous with “differently-abled” since all participants in an event like the marathon seek self-assurance and work towards goals (as simple as finishing the course). So too does every body have the ability to reach that goal, in different ways, even if that means having a support guide, a modified pair of shoes, a comedic poster or a catchy song lyric to get there. We all have the ability to cross our own finishing lines, and in doing this, draw on support from one another and the potential in ourselves.

Not everybody can run a marathon. To successfully complete a marathon requires physical discipline, energy, unrelenting assistance, support and guidance; these do not derive solely from on an “unbodied” device (Smith and Vonthethoff, 2017).

In this research report, I have argued that human experience and the multivalent engagements that go beyond what (bio)technology can offer are worthy of further consideration as enabling factors in sports participation, for individuals with and without physical disabilities. Assistive

features can aid in bettering one's physical performance, through the collecting and reading of numerical inputs and outputs, especially for those who base their ability on "facts" premised on Toni's "law of averages." But these devices do not engage cognitively or emotionally (Bi et al., 2019). In depending on such technology, our embodied physiological sensations, sensorially enhancing environments, and sense of self and togetherness, established through personal engagements, are rendered irrelevant and meaningless unless they can be translated into quantifiable data. However, the quality of human experience and human connection needs to be brought into consciousness if we are to fully realise the potential for human capacity, in the role of this capability, and in accepting that each body is different from the next. By returning to reconsidering "assistance" and "support" within the domain of physical performance as social and technical, I reveal how – from a Global South perspective (Comaroff and Comaroff, 2012; Lupton, 2017) – we are able to transcend the normative digitised and algorithmic states of health. This is a step in the right direction, even if you need a metaphoric Simon or Toni to help you along the way. My research acknowledges the multivalent nature and embodiment of assistance and support that collapses the ability and disability binary, and allows us to move towards a continuum that is fully inclusive of the complex human experience and the nuances associated with it, and so to accept what it means to be truly and compassionately human. The incentive – barring the monetary rewards system – is not in achieving predetermined goals, but in watching your son/brother with a physical disability cross a marathon finishing line, knowing that as much as you supported him to get there, he also guided you along the way, pole-pole.

Appendix

Appendix A:



INFORMATION SHEET

Physically Active Participants

Project Title: *Sensors and Senses*: Understanding assistive technologies through an analysis of embodied experiences. [working title]

My name is Gabriella Serra and I am a Masters' student in Anthropology at the University of the Witwatersrand. Thank you for your interest and willingness to participate in my Master's research. The aim of my research is to engage with individuals about their experiences of assistive technologies and how it is being utilised in achieving certain physical performance goals.

This research has been approved by the Department of Anthropology and the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (WITS).

Name of the researcher:

Gabriella Serra

Outline of research:

This research will describe and analyse the experiences of technology users and how they make use of such devices as forms of assistance in sport and fitness.

I wish to illustrate how different forms of assistance are utilised by different bodies in hopes that it will create a discussion around sports participation and social inclusion. I would like individuals to be able to narrate their personal experiences with embodied knowledge and assistive technologies.

How the information will be used:

The information will be used as part of the qualitative analysis for my final Master's research paper.

The role of the participant in the research:

The participant is required to engage in at least one semi-structured interview – which if consent is given, will be audio-recorded.

Anticipated risks which may result from participation:

Potential risks will be avoided through negotiating consent and ensuring anonymity. If at any time the participant chooses to no longer participate in the research process, all acquired information will be discarded and no mention of the participant's input will be discussed in my final Master's research paper.

Cost of payment involved:

N/A

Terms of participation:

If you are interested in participating in my research, please indicate by signing and dating the consent forms provided. Verbal consent will initially be negotiated, and written consent will be finalised. Anonymity will be reiterated throughout the research process; the participant will only be referred to by their pseudonym in field notes and in the final research paper.

By participating in my research, you are free to leave the process at any time without any negative consequences.

Thank you for your interest in participating in my research. If you have any further questions about this research or any information presented above, please feel free to contact me or my supervisor, Lenore Manderson:

Gabriella Serra

Email: gabi.serra01@gmail.com

Cell: 071 154 7863

Lenore Manderson

Email: Lenore.Manderson@wits.ac.za

Tel: (011) 717 3430

Appendix B:



INFORMATION SHEET

The New York City Marathon Participants

Project Title: *Sensors and Senses*: Understanding assistive technologies through an analysis of embodied experiences. [working title]

My name is Gabriella Serra and I am a Masters' student in Anthropology at the University of the Witwatersrand. Thank you for your interest and willingness to participate in my Master's research. The aim of my research is to engage with individuals about their experiences of assistive technologies and how it is being utilised in achieving certain physical performance goals.

This research has been approved by the Department of Anthropology and the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (WITS).

Name of the researcher:

Gabriella Serra

Outline of research:

This research will describe and analyse the experiences of technology users and how they make use of such devices as forms of assistance in sport and fitness.

I wish to illustrate how different forms of assistance are utilised by different bodies in hopes that it will create a discussion around sports participation and social inclusion. I would like individuals to be able to narrate their personal experiences with embodied knowledge and assistive technologies.

How the information will be used:

The information will be used as part of the qualitative analysis for my final Master's research paper.

The role of the participant in the research:

The participant is required to engage in at least one semi-structured interview – which if consent is given, will be audio-recorded.

Anticipated risks which may result from participation:

Potential risks may include the unintended re-telling or re-living of past traumatic events. If this is the case, necessary precautions will be taken; the interview will be intermittently paused, and the participant will be requested to seek either psychological therapy or trauma counselling. Once the participant feels able to re-enter the research process, our interview will continue, and no mention of the trauma will be redressed in my final Master's research paper.

To avoid possible marginalisation and categorisation, I will ask the participant about how they self-identify with regards to their physical impairment. My intention will be to present the participant with the noted distinction between “impairment” as a physical condition and “disability” as an experience of social exclusion. Identifying as “impaired” will only denote one's physical condition whereas identifying as “disabled” will suggest a vulnerable positionality and should proceed with caution, constantly discussing with my participant their desire to participate in my research and actively negotiating consent.

Cost of payment involved:

N/A

Terms of participation:

If you are interested in participating in my research, please indicate by signing and dating the consent forms provided. Verbal consent will initially be negotiated, and written consent will be finalised. Anonymity will be reiterated throughout the research process; the participant will only be referred to by their pseudonym in field notes and in the final research paper.

By participating in my research, you are free to leave the process at any time without any negative consequences.

Thank you for your interest in participating in my research. If you have any further questions about this research or any information presented above, please feel free to contact me or my supervisor, Lenore Manderson:

Gabriella Serra

Email: gabi.serra01@gmail.com

Cell: 071 154 7863

Lenore Manderson

Email: Lenore.Manderson@wits.ac.za

Tel: (011) 717 3430

Appendix C:



INFORMATION SHEET

Support Guides

Project Title: *Sensors and Senses*: Understanding assistive technologies through an analysis of embodied experiences. [working title]

My name is Gabriella Serra and I am a Masters' student in Anthropology at the University of the Witwatersrand. Thank you for your interest and willingness to participate in my Master's research. The aim of my research is to engage with individuals about their experiences of assistive technologies and how it is being utilised in achieving certain physical performance goals.

This research has been approved by the Department of Anthropology and the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (WITS).

Name of the researcher:

Gabriella Serra

Outline of research:

This research will describe and analyse the experiences of technology users and how they make use of such devices as forms of assistance in sport and fitness.

I wish to illustrate how different forms of assistance are utilised by different bodies in hopes that it will create a discussion around sports participation and social inclusion. I would like individuals to be able to narrate their personal experiences with embodied knowledge and assistive technologies.

How the information will be used:

The information will be used as part of the qualitative analysis for my final Master's research paper.

The role of the participant in the research:

The participant is required to engage in at least one semi-structured interview – which if consent is given, will be audio-recorded.

Anticipated risks which may result from participation:

Potential risks will be avoided through negotiating consent and ensuring anonymity. If at any time the participant chooses to no longer participate in the research process, all acquired information will be discarded and no mention of the participant's input will be discussed in my final Master's research paper.

Cost of payment involved:

N/A

Terms of participation:

If you are interested in participating in my research, please indicate by signing and dating the consent forms provided. Verbal consent will initially be negotiated, and written consent will be finalised. Anonymity will be reiterated throughout the research process; the participant will only be referred to by their pseudonym in field notes and in the final research paper.

By participating in my research, you are free to leave the process at any time without any negative consequences.

Thank you for your interest in participating in my research. If you have any further questions about this research or any information presented above, please feel free to contact me or my supervisor, Lenore Manderson:

Gabriella Serra

Email: gabi.serra01@gmail.com

Cell: 071 154 7863

Lenore Manderson

Email: Lenore.Manderson@wits.ac.za

Tel: (011) 717 3430

Appendix D:



CONSENT FORM

Interview and audio-recording

Project Title: *Sensors and Senses*: Understanding assistive technologies through an analysis of embodied experiences. [working title]

My name is Gabriella Serra and I am a Masters' student in Anthropology at the University of the Witwatersrand. Thank you for your interest and willingness to participate in my Master's research. The aim of my research is to engage with individuals about their experiences of assistive technologies and how it is being utilised in achieving certain physical performance goals.

This research has been approved by the Department of Anthropology and the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (WITS).

Name of the researcher:

Gabriella Serra

I hereby agree to participate in Gabriella Serra's Master's research titled, "*Sensors and Senses*: Understanding assistive technologies through an analysis of embodied experiences." [working title]

By participating in this research, I agree to the following:

- I understand that I not obliged to participate in this project.
- I understand that I may withdraw from participating in this project at any time.
- I understand that my identity (name, race) will not be mentioned in this research. I agree to be referred to by pseudonym to ensure the safety of myself.
- I understand that participating in this research process will not intervene with my personal commitments.
- I understand that this research is for Masters' qualification purposes.

By participating in this research, I agree with having my interview audio-recorded. Please tick where appropriate:

Yes	
No	

By consenting to this research, I have received and familiarised myself with the following:

The details of the research, my role as a research participant and the risks involved as noted on the Information Sheet.

.....

Name of participant:

.....

Signature of participant

.....

Date

.....

Signature of researcher

.....

Date

Appendix E:



<https://www.timeout.com/newyork/things-to-do/nyc-marathon-route>

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