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Disability, sport and men’s narratives of health: A qualitative study

By

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(In-press)

Health Psychology
Objective: Very little research has been conducted that examines men, sport, masculinities, and disability in the context of health. Readdressing this absence, this paper examines the health narratives told by spinal injured men and the work narratives do on, in, and for them.

Methods: In-depth life history interviews and fieldwork observations with men (n=17) who sustained a spinal injury through playing sport and are now disabled were conducted. Qualitative data were analyzed using a dialogical narrative analysis.

Results: Stories told about health characterized a style of embodied actions choices that anticipated a certain type of narrative, that is, an emergent narrative. The men’s narrative habitus, fashioned through the process rehabilitation, predisposed them to be interpellated to care about health. To uphold hegemonic masculinities the men also did not care too much about health. The analysis also reveals the work narratives do on, in, and for health behavior, masculine identities, resilience, leisure time physical activity, and body-self relationships. Implications for health promotion work are highlighted.

Conclusions: The paper advances knowledge by revealing the emergent narrative of health. It reveals too for the first time the way certain contexts and masculine identities create a new subject of health that cares about doing health work, but not too much. Building on the theoretical knowledge advanced here, this paper contributes to practical understandings of men’s health and disability by highlighting the potential of narrative for changing human lives and behavior.

Keywords: Disability; men’s health; resilience; narrative; physical activity
Disability, sport and men’s narratives of health: A qualitative study

There are numerous health benefits to playing competitive or leisure time sport. But, in some instances, and more often to men than women, it can also result in disability and long-term health problems. The purpose of this paper is to examine the type of health narrative(s) told by a group of men who sustained a spinal cord injury (SCI) through engaging in leisure time physical activity and are now disabled. It too examines the work these narratives, as ‘actors’ in Frank’s (2010) terms, do in shaping the men’s health behavior.

Examining disabled men’s narratives of health is significant and timely. First, as Frank (2010) argued, the narratives that circulate outside us in culture inform our sense of health and what we know about it. Hence, a person’s understanding of health comprises which narratives they take on board from what is available in the cultural menu. Moreover, these narratives shape our health behaviors. They have the capacity to do things. That is, narratives act on, in, and for people: they tell people who they ought to be, who they might like to be and who they can be, “affecting what people are able to see as real, as possible, and as worth doing or best avoided” (p. 3). This is not to deny that health has a biological basis. Nor is it to say narratives determine health behavior or that people are docile selves who passively accept any story offered. But, the telling of health stories necessarily involves the selection from the cultural menu of some over others, and some parts of the same story over others depending on the circumstances (Frank, 2010). Thus, as Frank (2006) put it, “Health for any person is a fluid process of living with certain stories and taking on board some new stories, while leaving many competing stories to float in the river of not-for-me” (p. 424). Accordingly, narrative inquiry is adopted in this study.

Second, examining disabled men’s narratives of health is also significant and timely as we have very little empirical knowledge on men, SCI, sport, and disability in the context of health (Burns, Hough, Boyd, & Hill, 2010; Robertson, 2004). Yet, sustaining a SCI is gendered and a major risk to health. Relative to women, men are four times more likely to sustain a SCI, and constitute 82% of those that do (Burns et al., 2010). Further, those that suffer a SCI are at a
heightened risk of mental ill health and costly secondary health conditions, including cardiovascular disease, pressure ulcers, and obesity. They too are five times more likely to commit suicide than those in the general population (Soden et al., 2000). Despite all this, and even though tens of billions of dollars is annually spent on spinal health care needs globally, as Kehn and Kroll (2009) noted, spinal injured people have rarely featured as a target for health promotion efforts.

The recent work by Martin Ginis et al. (2010, 2011) within sport and exercise sciences has underscored the need for work on SCI, men, and health. Complimenting the growing research on elite competitive disability sport (see Martin, 2010; Smith & Sparkes, 2012), there has been a recent interest in SCI and leisure time physical activity (LTPA). LTPA is physical activity that people choose to do during their free time, such as playing recreational sports, exercising at a fitness center, or going for a wheel. Despite the health benefits of doing such activities, in the first large population-level data study on the amounts and intensities of LTPA spinal injured people did, Martin Gins et al. noted that SCI leads to a reduction or cessation of participation in LTPA among men. They further reported that daily LTPA levels are low in men with SCI. In light of all this, work that uses not just data but also theory was called for to better understand the complexities of SCI, gender, and health. In health psychology, as well as the sociology of health and illness, a similar call has been made.

As noted in Gough and Robertson (2010), using the social relational theory of gender by Connell (1995), early work in health psychology and the sociology of illness proposed that subscription to hegemonic masculinities, whether overt or ‘complicit’, often has a powerful negative impact on health and health-related behavior (e.g., high alcohol consumption). The concept of hegemonic masculinity refers to dominant notions of gendered identities that are social relational in nature, made relevant by people in everyday contexts, and influenced by wider cultural norms (Connell & Messerschmidt, 2005). Recently a small amount of empirical work has, however, suggested that ‘doing’ masculinity relative to health behaviors is more dynamic and contradictory than previously thought. For example, de Visser, Smith, and McDonnell (2009), and
Robertson, Sheikh, and Morre (2010) argued that some men might both subscribe to hegemonic masculinity and legitimately engage in healthy behaviors (e.g. exercising or avoiding alcohol). Similarly, Sloan, Gough, and Conner (2010) noted that when men take up some health behaviors censure does not automatically result, positioning these men as ‘subordinate’ or ‘marginalized’ (Connell, 1995). Thus, as these authors suggested, the traditional masculinity-health relationship, in which masculinity has a negative impact on health behavior, is not as straightforward as often proposed. As such, they recommended that if men’s health promotion activities are to have real impact, more theoretically nuanced empirical research on men’s health is needed.

Methodology and methods

Philosophical assumptions and data collection methods

The design of this study is underpinned by ontological relativism (i.e. reality is multiple, created, and mind-dependent) and epistemological constructionism (i.e. knowledge is constructed and subjective). After gaining University ethical approval for the study, a purposive sampling strategy was used to recruit participants. The criteria that guided inclusion in this sampling process were people who a) had sustained a traumatic SCI doing LTPA, b) are disabled, and c) are aged 18 years or over. To recruit this sample, an open letter was placed in UK disability newsletters/internet sites, inviting people who met the sampling criteria to take part in the study. Reflecting the fact that the vast majority of spinal injuries happen to young men, 17 Caucasian males and 5 females aged between 21–37 years were recruited. Given the purpose of this paper is to understand what health means to men, the focus here is on the 17 males.

All participants were involved in life history narrative interviews. In each interview, the researcher invited participants to tell stories about their own lives and how it is lived over time. Participants were interviewed in their homes on two occasions within three months of the first interview, with each interview lasting from two to six hours. All were interviewed twice for these reasons. A researcher can analyze data collected from the first interview and, based on the results, in the second interview ask follow up questions, probe deeper, and invite reflections on their
interpretation’s. In so doing, the researcher can collect richer data than he or she could in just one interview, enabling in turn a more credible, in-depth, and complex understanding of participant’s lives. Second, due the process of developing trust and rapport, two interviews provides more space than one to engage with a person on the terms they choose.

Concurrently with interviews, 37 hours of participant observation data was collected. For example, the author participated in gym sessions with some participants, went food shopping with others, observed interactions in a bar, and collected small stories from men over coffee in cafés or during a meal in their family home after an interview. Data was recorded either in situ or later that day using field notes. The method of participant observation was chosen because it allows the researcher insight into the mundane, the typical, and occasionally extraordinary features of everyday life that a participant might not feel worth commenting on in an interview. Combining observational data with interview data also enables researchers to understand not just what a participant says they do, but also what they do in everyday life. Thus, the combination of data can act as a resource to generate a more complex understanding of people’s lives.

Narrative Analysis

A Dialogical Narrative Analysis (DNA) was used to make sense of the data collected in an iterative fashion (Frank, 2012). In a DNA, stories are examined not as mere products of telling. The story itself is interpreted and what stories do analyzed. The analyst’s attention focuses on how a story is put together and what kind of story is being told (as per a structural analysis). It also turns to “the mirroring between what is told in the story—the story’s content—and what happens as a result of telling that story—its effects” (Frank, 2010, pp. 71–72).

The process of doing a DNA (see Frank, 2012) entailed the author first immersing himself in the data by reading and re-reading transcripts and field notes as well as listening to the recorded interviews. A focus here was kept on stories. These were then translated into images. As Frank (2010) noted, a “step in interpretation as a work of going into the story is to stop reading or listening and see, then asking how the story positions you to see” (p. 106). Next, conceptual
comments were made on the transcripts and fieldnotes. For example, in this process stories were identified and how and why a person tells the story the way they do commented on. Theoretical and procedural memos were used throughout the research process. These also helped understand relations and any differences between observational and interview data. The analytic process moreover comprised writing and working with various dialogical questions. In DNA, writing is a form of analysis. Dialogical questions asked throughout included, resource questions (e.g., What resources does the storyteller draw on to shape their subjectivity?) and connection questions (Whom does the story connect the storyteller to? Who is placed outside this connection?).

Validity: Ongoing list of criteria for judging the quality of qualitative research

This study was guided by a variety of criteria as assembled in Tracey’s (2010) review of what constitutes “excellent qualitative work” (p. 837). These criteria included, the worthiness of the topic, resonance, the significant contribution of the work, and rich rigor (e.g. weaving together appropriate concepts and theories). The study also used an audit trail to enhance transparency (e.g. a colleague independently scrutinized data collection and theoretical matters). Further, credibility was sought through participant reflections on the researchers interpretations of the data. Participant reflections are however less a test of research findings. They are an opportunity for dialogue on the believability of interpretations, providing a spur for richer and deeper analyses.

Results

Without seeking to finalize the participants, the results are presented as follows. First, the dominant story of health told by men is illuminated. A ‘should care’ approach to health, ‘but not to much’ is in turn then highlighted. Emphasized next is LTPA as health work for ‘caring about health, but not too much’. The paper concludes with theoretical points and practical implications.

Understanding health: Adapting to disability and the emergent narrative

Differing from the work by Sloan et al. (2010) that found ‘healthy able-bodied men’ disavowed a direct interest in talking/thinking about health, all men here presented themselves in the stories told as consciously aware of, and thinking about, their own health. This is exemplified
in the following story from John, a 33 year old middle class employed male who lives with his girlfriend and sustained a SCI five years ago surfing.

I: How would describe your life now John, your everyday life?

John: Well, not boring. But, my, my life is all about, not all about, but my health is a big part of my life, and everyday life. It’s something I can’t hide from, and it’s about learning to adapt, and managing my health each day, daily. It takes up a lot of my day. I don’t think about it every minute of the day, don’t get me wrong. But my health is something I think a lot about now, and I spend time each day doing things to manage it. I never used to. I was sport mad, but health wasn’t something I thought about because, because unlike now it wasn’t an immediate concern for me. It’s not something I thought about, maybe because I was healthy. Now though I have to care about my health otherwise, well, there are a lot of reasons why, and I’ll come back to these. What, y’see I know my health is, well, it is what it is, it’s there, and I can’t change what happened to me, and there is no miracle cure. I’ll be like this forever most likely, so it is what it is. There’s no point wishing otherwise. But that’s not saying you give up. My health, like breaking my neck, is what it is. But, and my point is, I know too I should care about it, and I do care about my health. I probably don’t do enough though. Maybe that’s because I care but not too much. It’s weird y’know. It’s like part of my DNA.

I: What do you mean?

John: There’s no, no escaping the fact I should care about my health. I feel I should, deep down. It was drilled into me straight after breaking my injury I should care about my health, and I can’t get away from feeling, that I should care. But, yeah, I do care, but I feel too I shouldn’t care too much about it, my health, both physical and mental. That’s what I mean. I do care about my health, I’ve a wide open future after all, but not too much.

John’s comments typify the stories of the other men in this study. They differ though from the stories analyzed in other SCI research. In this research (Smith & Sparkes, 2008; 2012), some
participants told a quest narrative whilst others told a restitution story wherein a return to a past healthy able-body was fervently sought. In contrast, one participant in the research by Smith and Sparkes (2008, 2012) told the anti-narrative of chaos. For that person, life was foreclosed, funneled and imagined as never getting better. Further, their embodied action choices – the choices the body-self then acts out (Frank, 1995) – lacked desire to actively do health work (McCoy, 2005) to care for and improve health.

Differing from the chaos, restitution, or quest narratives, the story the men in this study told of health can be described as a particular style of embodied actions choices that anticipate a narrative. This story of health might then be named an emergent narrative. Exemplified in John’s comments above, and others as this paper unfolds, this is a narrative that is open to whatever life brings, with disability. The person telling an emergent narrative does not want to specify too much of that narrative. They leave it open to emerge. Thus, like a chaos narrative, an emergent narrative is an anti-narrative. It is a mode of narration that lacks a plot. It has little sequence orientated toward the future, only (or mainly) a concern with the immediate present. For example, the men here dwell on immediate, pragmatic concerns of body care. But they are open to whatever their life brings, willing to let a life/narrative trajectory – where that life was, what’s happened, where’s it going - take care of itself; the men neither need nor want a future tied to quest or restitution narrative, as that would circumscribe their lives. Accordingly, an emergent narrative is an anti-narrative, yet it differs from chaos. An emergent narrative is productive, not lacking; optimistic, not funneling down; open, not narratively foreclosed.

To facilitate an emergent narrative, to remain open to whatever their life brings, the men do certain health work. This included caring about their health. The productive desire to care for ones health that helped facilitate open narratives was not, however, simply held inside the men’s body or mind. It was partly a product of a specific social process. That is, narrative interpellation. This is the social constitutive process where individuals are ‘hailed’ – called - by people and their stories to acknowledge and respond to ideologies to be certain individuals as subjects (Frank,
The men in this study were interpellated to be the sort of body-self who ‘should care about health’ (but not too much). For example, John’s repeated emphasis on “should care” display’s interpellation. Of course, like the other men he could have resisted being hailed and avoided selecting taking on board a story of caring for health. But, this was not the case.

**Should care about health: The material body and narrative habitus**

One reason for feeling one should care for their health was tied to the material body. Post-SCI the body is vulnerable to problems like pressure ulcers. To avoid such health problems, daily the body should be cared for. Another reason why the call to should care about health had force, and was not passed over by the men in favor of other health stories, relates to narrative habitus.

Adapting Bourdieu’s (1992) work, narrative health habitus (Frank, 2010) is an acquired embodied disposition formed in the context of people’s social locations to hear some health stories as those that one should listen to, should tell, should be guided by, and should pass over. It describes the embedding of stories about health in bodies and the embodied sense of attraction, indifference, or repulsion that people feel in response to stories that leads them to define a certain story as for them or not. Narrative habitus, therefore, “is the unchosen force in any choice to be interpellated by a story, and the complementary rejection of the interpellation that other stories would effect if a person were caught up in them” (Frank, 2010, p. 53).

The men’s narrative habitus that predisposed them to be called to certain stories in which one should care about their health and not others could have been partly acquired through their years of socialization pre-SCI in LTPA. However, following SCI the body that one has and is changes dramatically: it is a ‘new’ body. With this new body come bodily care concerns never experienced. The men learnt how to live with being and having a different body, and how to manage new bodily concerns, within the ‘narrative environment’ (Gubrium & Holstein, 2009) of rehabilitation. As Bill, a 29 year old unemployed single male who sustained a SCI 8 years ago playing rugby, said:
Bill: I do still feel under some pressure to care about my health, though, I’ll say in second why. And my mum, my dad, carer, even friends sometimes do remind me. And I guess sometimes I do need reminding because, really, I care, but not that much, not too much anyhow. Really though I don’t need reminding. It’s like a voice in the back of my head always telling me I should look after my health, do this, don’t do that, be careful of pressure sores, you’ve lay in the same place for a stretch, move, you need to exercise.
I: And did this voice come from your sporting days, when
Bill. No. I never cared about my health then. Maybe I gained a little knowledge. But all what I learnt before is pretty useless after breaking your neck. You’re starting over again. I was like a baby again, and needed to learn everything afresh, new things to adapt to this new body. And it was drilled into me in rehab that I should care. Physio’s, nurses, psychologists, doctors, even other guys in there, and other [disabled] guys who were doing peer support, all drilled into me I should care about my health. And they were quick to remind me too, well, staff were, that if I didn’t look after myself I’d end up back in rehab, and that would be my fault, so they better not see me once I left.

As the comments above illustrate, whilst family, friends, and carers were important in supporting a care about health approach, most powerful in predisposing the men to this approach was the process of rehabilitation. As newly disabled men, the participant’s “grew up” in the rehabilitation environment on stories health care professionals and other disabled men told about caring for a ‘new’ body. Through this process, they were interpellated to be a new ‘subject of health’, with different embodied concerns. For example, interpellation is evident when Bill says, “It’s like a voice in the back of my head always telling me I should look after my health.” It is also emphasized in comments like caring for health was “drilled into me.” Like Bill and John suggested earlier, what is being ‘drilled’ is a new subject who is being called upon - and now calls upon himself - to take ‘health’ with a new seriousness. In so doing, the stories that informed the men they should care about being healthy worked in and on them. They got under their skin
(Frank, 2010), becoming a narrative habitus of health. Arguably strengthening this process is a certain cultural neoliberal health discourse that circulates not just in the rehabilitation context, but also the broader cultural landscape the men move into upon leaving rehabilitation. This discourse is one which calls on people to be a dutiful citizen who takes individual responsibility for their own health – and thus are a morally ‘good’ social self (Robertson, 2006).

The men’s adoption of a ‘should care approach to health’ and the emergent story they embodied should not however be viewed deterministically. While people can have an embodied disposition to caring about health, and may be interpellated to be a subject who is called on to care, people are rarely docile selves who passively accept any story. That said, choosing from health stories necessarily involve the selection of some over others, and some parts of the same story over others depending on the circumstances.

*Should not care about health too much: Upholding masculinities*

Helped by the open nature of their emergent story, the men selected and chose to take on board, *after* a ‘should care approach to health’, another approach that became part of their story of health. This was a ‘should not care too much’ approach to health. For example, Jay, a 32 year old employed father of two who sustained a SCI four years ago diving, said in response to be asked, “What was life like in rehab?”

Sometimes a belly of laughs. But mostly it was boring. And it was all about learning again to look after yourself, it was like being a baby again, but being conscious, being always taught you need to care much more now about your health because of the injury. And I do care now. Before the accident I didn’t, even though I was very sporty, and now I feel deep inside me I should, I should be good and be responsible for my own health. But I don’t care too much about my health either….I’ve seen a few guys with injuries like mine moaning about their health, far too obsessed with it, and if you ask me, don’t have balls to get on with life. So what they do is care too much about their health, go over the top. Not me. I care for sure, I have to, but not that much.
Whilst the men did care about their health, they also felt, as the comments in this paper illustrate, they should not care about their health too much. Among various things, this latter approach worked for the men to uphold hegemonic masculinities - those forms of masculinity that are dominant at any one time in a given community. As research has shown, hegemonic masculinities can come under threat when men care too much about health (Robertson, 2006). ‘Real men’ don’t care about health that much; women do, but not ‘real men’. Thus, by taking on board a ‘shouldn’t care too much’ approach, and fitting it into their health stories, the men in this study may be said to uphold hegemonic masculinities.

Upholding masculinities was given additional force when the men used the ‘should care, but not too much’ health approach to (dis)connect with others. For example, James, a 26 year old employed single male who was ‘very sporty’ before sustaining a SCI surfing, said:

My health is important to me now. But I’ve seen a few men after injury ignore their health, not look after themselves. And there are others who go the other way, overly concerned about their health, caring too much. None of that’s rational. You gotta care for sure, but you gotta too have the courage and discipline to manage your health, like I and my mates do, to be able to step back and say I’m bothered about my health, but come on, not that bothered. If I went too far either way, it’s no good. I can’t be around those guys who go too far either way, fussing, worrying about their health or are too stupid, lack the discipline to, to take care of themselves. A man’s got to man up on these things. So I just stick with the guys who have my attitude.

As part of the evolving narrative, therefore, caring about health but not too much seemed to further work on and for the men by connecting and disconnecting them with other people in ways that upheld gendered relations. In terms of connecting, the participants affiliated with those men who, like them, displayed the ‘courage’, ‘discipline’, and ‘rationality’ to care, but not overly care about health. However, those who didn’t display such masculine signifiers or codes as ‘courage’,
‘discipline’, and ‘rationality’ in relation to health were deemed ‘not real men’. They were rendered external, other, to the participants, arguably marginalizing or subordinating them in the process.

In addition to (dis)connecting with people, upholding masculinities was given extra force by linking the ‘should not care too much about health’ approach to resilience. Consider the following words from fieldnotes taken in a spinal rehabilitation exercise center when observing Pete, a 33 year old male: “Speaking to a male trainer after a short training session, Pete [SCI diving 4 years ago] said: ‘I’ve adapted well to my injury, and am positive about my future, whatever it might be or bring. I’m resilient now which means I can adapt in a positive way, and which means I don’t need to care that much about be active, or caring about my health that much.”

Likewise, Tom, a 30 year old married man who worked part-time after sustaining a SCI playing rugby said in an interview after being asked about how he coped with spinal injury:

Tom: I cope pretty well I think. I’m resilient, and can bounce back from most things. I did after breaking my neck, so I’ve got this belief that if things go wrong now then no problem. Unlike some men I’ve seen, I’ve the strength to bounce back, and I don’t need to rely on others to do that…Take my health, it’s important now. I know I should take care of my own health. I do. No way do I want to end up back in hospital, taking an ear full from the staff for one, taking up another bed. But when you’re highly resilient like I am, then you know, I know I can afford to be a bit relaxed, and not care too much. I know that if something goes wrong, or I have an accident that means I get a pressure sore or infection, or feel depressed, then I’ll be able to bounce back. I have that in me.

I: So if you became ill, you

Tom: I’m resilient, so I’ve got the strength to bounce back if I became ill. Things would be under control, so I can afford to not care that much about my health…

I: By resilience, you mean?

Tom: I can bounce back, recovery when I’m really down in the dumps, or gave health problems from not looking after myself. I can ‘man up’. I don’t go further down into some
black hole. I pick myself up, and grow, positively adapt, not sink further…Resilience isn’t about mental toughness. It’s much more. It’s about growing, positively adapting, learning, and knowing I’ve got the strength to recovery, can ‘man up’ which, which means too I know I can give myself some slack, and yes care, but not too much about my health.

Resilience has been conceptualized in many different ways across the literature (see Reich, Zautra, & Hall, 2010). For the men here, it was about the ability to positively adapt to adversity, a risk, or illness (White, Driver, & Warren, 2010). It was a health resource that worked for them to recover quickly if illness or a health problem arose as a result of not caring about their health too much. But by linking resilience to masculine signifiers (strength, autonomy, control), and using the idiomatic verb ‘man up’ (i.e. to do the things a good man is traditionally expected to do, such as taking responsibility for the consequences of one’s actions), the men also reframed resiliency as a gendered resource. In so doing, resilience not simply worked for the men as a health resource. It also worked for them by enabling each to accrue masculine ‘capital’ (de Visser et al., 2009). They gained capital from doing masculine things like ‘not caring too much about health’ and using masculine signifiers/idioms in the stories of resilience they tell. In certain social contexts (fields) such masculine capital, as de Visser et al. argued, is a vital source of authority and power. It “can be used to compensate for non-masculine behavior in other domains” (p. 1055). Equally, and dangerously, it can do work on others, marginalizing or subordinating them.

Caring for health, but not too much: Leisure time physical activity as health work

As part of caring about their health, and to facilitate the emergent narrative, the men engaged in various forms of health work (McCoy, 2005). For example, they largely ate healthy food, limited their alcohol consumption, and visited a doctor when concerned about an imaginable spinal secondary bodily health condition (e.g. possible pressure sore/ulcer). But, the most common health work the men did was LTPA. This included wheeling long distances in the natural environment, indoor gym work, and lifting weights in the home. For instance, Jack, a 32 year old employed male who lives with his girlfriend and suffered a SCI 7 years ago playing rugby said:
I lift weights now, which has helped me feel more confident, and instead of going in the car, I wheel once a week to mum’s house, even in bad weather, and mum’s house is a good 30 minutes away. And I try and exercise at least once again, another time during the week. So I stay pretty active. It’s about caring for my body, taking responsibility for my own health. And after exercise I feel good. It lifts my mood, keeps my body feeling good, and I like exercising as I feel I’m looking after my body, I’m being kind to it now, not hating it like I did straight after the accident, which is part of adjusting to the injury I think too. So I exercise, and psychologically get a lot out of it. I perhaps though should do more, but it can be difficult, cost, finding places to train, and truth be told I care about health, but should care a lot more than I do.

All the disabled men engaged in LTPA in order to care for their physical health that they were narratively interpellated to be. Physical activities were done too for the positive impact they could have on subjective wellbeing, notably self-esteem and mood. Similarly, the men engaged in physical activities for reasons oriented with what Watson (2000) termed experiential embodiment. This is a mode embodiment concerned with experiencing positive emotions, notably embodied feelings of confidence, optimism, fun, and vibrant physicality. The men were motivated also to be active for bodily appearance reasons, specifically developing muscularity. Another motivating factor the men gave for doing LTPA was framed in terms of body-self compassion. A relatively new conceptualization of health within the literature, body-self compassion refers to an attitude or feeling of kindness and understanding towards one’s body and self (Berry, Kowalski, Ferguson, & McHugh, 2010). For the men, it specifically involved taking ownership of one’s body and appreciating one’s unique body rather than engaging in harsh criticism of one’s perceived imperfections and limitations. Body-self compassion was also linked with greater feelings of social connectedness and life satisfaction. For example, there was a diffuse sense among the men that exercising energized them to participate in life - moving them from disability as lack to a regained sense of being a productive body, able to wheel to see family, work, and socialize.
Despite doing LTPA for the impact it could have on subjective wellbeing and the lived body, the data suggested that as time went on certain benefits accrued from being active became more salient for engaging in LTPA. These benefits revolved around control, independence, and functionality. For example, Matt, a 26 year old employed single male who sustained a SCI diving said after being asked why he exercised:

Matt: I started exercising, doing some fitness work in my house, though I wanted to go to the gym but the facilities weren’t geared for me, for disabled people, and other places have been pretty bad too, distance, and accessibility mainly. But I enjoy wheeling, and weights, as since leaving rehab I’ve felt I oughta take care of my health, physical and mental health. It’s the right thing to do. And I still do those types of things, to look after my health, but since starting being active again I’ve noticed a bunch of other benefits. I’ve definitely more control over my body, feel more confident, doing more activity has helped get more function back, which with control has meant I’m more independent. That’s, it was a bonus of sort back then, but now it’s what keeps me going, keeps me exercising. No way do I want to be dependent on others or lose what control and function I’ve built up. No, I’ll keep exercising, lifting weights.

I: Are there any other reasons you keep exercising

Matt: Sure. Appearance a little. I certainly don’t want to get a belly, I’m too disciplined for that anyhow. But I exercise mainly because I feel I should, to care for my health, and there are added benefits like more function and independence. That’s huge for me. It’s meant I’ve been able to work in a demanding job and get my self-worth back as a man. Every man needs to work and exercising has given me more energy, more independence, which means I can work, and work harder, and can now contribute to society.

Likewise, consider the following fieldnotes taken after interviewing Henry, a married unemployed father who sustained a SCI playing rugby:

Finished interviewing Henry. We were sat having tea afterward in his kitchen when his
young son burst into the room. Daddy, Daddy, can we throw the ball now. Let’s throw the ball Daddy. Henry smiled and asked if I’d join them throwing a rugby ball around in the back garden. As his son dashed out of the door to get the ball, Henry smiled, and said, ‘That’s why I go to the gym, to do this with my son, to be a proper dad.’

For the men, the feeling that one should care about health helped motivate them to do LTPA; it was part of their narrative habitus that predisposed them to care for their health and engage in certain health behaviors. But, as highlighted above, with engaging in physical activity also came increased bodily control, functionality, and independence. These over time came to subsume importance for motivating health behavior. In part, this was because control, functionality, and independence helped support having and being a pragmatic body (Watson, 2000). This is a mode of being that is concerned with the functional use of a ‘normal everyday body’ in order to fulfill, as the data above suggests, specific gendered roles (‘father’, ‘husband’, ‘worker’) required in the social world (Robertson et al., 2010). In this sense, again, health behavior was connected to masculinities.

Furthermore, the increased functionality, control, and independence gained through engaging in LTPA, and which upheld masculinities, were important as these bodily matters helped to manage impairment effects and minimize the psycho-emotional damage that can accompany these effects. As delineated by Thomas (2007), these two concepts are embedded in the social relational model of disability. This model theorizes disability as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing” (p. 115). Theorized in this way, impairment is recognized not simply as biological matter, as in many other disability models (e.g. social model). It is understood also as experienced and psycho-social. For example, as the following comments by Oliver, a single 27 year male who sustained a SCI playing rugby suggest, the intended or unintended social actions of able-bodied individuals in inter-personal engagements
with people who are impaired can impact negatively on those with impairments. This may include damaging their psycho-emotional wellbeing and concomitantly, their sense of masculinity.

I: How then do you feel, feel about your body now?

Oliver: The thing about spinal injury, about being disabled for me is that physically my body can’t do certain things, and that can affect my health, so I know from rehab, feel it in my bones every day I should care for my health, which, ok not that I look after my health like, like, not over, not too much, but you still have to give a damn otherwise I’ll be ill and most likely die. Though, I must admit, that doesn’t really factor into my day to day to thinking, death or that. It’s more, my health is always something I have to manage and adapt to regularly every day, and I do exercise now to help with this. And I’ve been surprised that, an unexpected outcome has been more control and more function, and independence then, so I try and stay active. I’m, with exercising, I feel, feel more confident, better about myself as a man because, well, there was a time when I was afraid, maybe nor afraid, but anxious that if I went out in public I might lose control of my bowels, not push myself to the bar, or I couldn’t pick something up at Tesco’s [a large retailer that sells food, clothing, and other goods], and I’d have to ask for help or someone would take it on themselves to help, sometimes without asking. That made feel useless. And, and there were a lot of times I couldn’t get up ramps because I didn’t have the strength to push myself up, and some people, ok they may have been well meaning, but they’d just see me struggling and push me up, again sometimes without asking. That made me feel like shit, useless, dependent, and I wouldn’t say I would sink into depression, but I felt dreadful, despondent about my life after those things. But now exercising means I can get up ramps by myself now, get to the bar, have more control, function, strength, and be more independent. I feel like a proper guy again.

Maintaining control, independence, strength, and functionality have historically been seen as related masculine attributes (Sloan et al., 2010). Equally, as the above comments illustrate,
lacking or losing these attributes when interacting with others following SCI can on certain occasions threaten masculinities and damage psycho-emotional wellbeing. To help offset such threats and damage, engaging in LTPA was useful for the men. Being active resulted in gains in strength, control, independence, and functionality, thereby working for the men by making connections with masculinities as well as sustaining wellbeing when faced with the negative social effects of having and being an impaired body in a society that privileges certain bodies over others.

A close inspection of the data would suggest this gender-health relationship was further demonstrated when the ‘shouldn’t care too much about health’ part of the emerging narrative was evoked in the men’s stories about LTPA. When asked about how much activity they did, each said they engaged in 20 to 30 minutes of some form of physical activity at a light to moderate intensity (e.g. lightly sweating) twice to three times a week. Observational data supports this. The men seemingly did not therefore meet recommended physical activity guidelines for disabled people. These guidelines recommend engaging in 20 minutes of physical activity at a moderate (e.g. light breathing) to heavy intensity (breathing heavy) for a minimum of 4 times per week (2 x aerobic and 2 x strength activity) (Martin Ginis et al., 2011). There were several reasons given by the men for not being as physically active as much recommended in these guidelines. Despite spinal rehabilitation hospitals/units emphasizing they should care about their health, in terms of LTPA they were given little information about what different activities they might do, where to exercise, and how much activity to do. When some information was gained outside rehabilitation via disability groups, the Internet, or friends, the costs to exercise and long distances to travel to gyms were barriers. Reverberating with the social model, a lack of accessible facilities was another key reason given for not engaging in more physical activity.

The most frequently given reason by the men for not engaging in LTPA, however, was embedded in the emerging story in ways that connected them to masculinities. In this story, the men not only felt they should be active in order to care for their health, but they didn’t need to be
very active – ‘that active’ - as they shouldn’t care about health *too much*, thereby upholding masculinities. Being active but not too much was further justified in gendered ways by drawing on the theme of what is known as ‘the supercrip athlete’ (Smith & Sparkes, 2012). A supercrip athlete is highly competitive person with an impairment who, with courage, hard work, and dedication, proves that through sport one can accomplish the impossible and heroically triumph over the ‘tragedy’ of disability. In such ways, the supercrip connects with numerous masculine signifiers or codes (e.g. disregarding pain, sporting, competitive, and courageous).

For the men here however, being a supercrip was resisted in ways that upheld their sense masculinity. The men perceived supercrips as doing (too much) activity in order to compensate for not having the resilience to adapt to SCI, for being pitiable at sport before SCI, and for being insecure internally as a disabled man. Exemplifying what all the men said, Perry, a 25 year old single male who suffered a SCI 4 years ago whilst playing rugby commented:

Perry: In rehab there was no mention about doing, about exercising, going to a gym, casual sport for just fun. There was the usual sports stuff, really competitive basketball and wheelchair rugby. I tried it, and even played some, some basketball when I left rehab. But I stopped pretty quickly.
I: Why?
Perry: The guys I played with all, I don’t want to speak bad of them, all wanted to play in Paralympics too, but they were over compensating for being in chair…Some hadn’t come to terms with their injury, some weren’t resilient enough to deal with the crap that life throws at you, and I know that most of them were pretty useless before, at sport I mean, before they were injured. Me, I don’t have anything to prove. I’m secure as a guy…I exercise, not enough, and know I should do more to stay healthy, but no, the guys who I played were just insecure and all talk.

Unequivocally sport can be a healthy ‘masculine’ behavior (de Visser et al., 2009). Athletes can trade their masculine capital to engage in healthy behavior, such as choosing to eat
healthier food. There are also many other positive social, psychological and physiological health benefits of engaging in disabled competitive sport that can mean one meets the call to care for the body-self (see Smith & Sparkes, 2012). But, for the men here, competitive sport was rejected as a potential activity to care for ones health. This could have been a dangerous strategy for them in terms of performing masculinity or meeting the call to care for health, as others often view disabled sport as a masculine activity (Smith & Sparkes, 2012). However, in the men’s eyes, sport was not associated with healthy ‘masculine’ behaviors. ‘Other’ men engaged in sport because they had failed to adjust to SCI, lacked resilience, were inadequate at sport before SCI, and/or felt privately insecure. In these ways, then, the men here not just fashioned reasons for avoiding playing sport or being active too much. They also were able to reject the traditional view of sport as supporting masculinity whilst positioning themselves as superior to supercrips, thereby rescuing masculinities and ensuring their masculine status in the context of healthy practices.

Concluding comments

Despite the need to promote healthy behavior among disabled people, there is scant work that empirically and theoretically link men, disability, impairment, and LTPA in the context of health. This was addressed here. In addition, the paper has made a contribution to the literature by identifying a new ‘narrative’ of health. This was named the emergent narrative. Differing from illness stories that are pervaded by mortality (Frank, 1995), this anti-narrative was characterized by an embodied desire to leave the future narrative open - not expecting restitution, but not understanding disability as chaos or a quest either. In adding a new type of story to the literature, and naming it, practical usages emerge. Naming types of narratives – even anti-narratives like emergent or chaos – often proves useful for disabled people to reflect on what story they have been telling—what enabled that story and how that story works on, in, and for them, affecting their life—what story they want to tell, and even more important, what story they were not telling, leading them to ask why not (Frank, 2012). Naming narratives “can authorize the telling of particular stories, and it can also liberate people from telling stories they no longer want to tell”
Furthermore, this is the first empirical research to critically investigate resilience and health among SCI males living in the community (White et al., 2010). In line with literature on able-bodied men (see Reich et al., 2010), it highlighted that resilience is a resource for promoting health and wellbeing. More uniquely, resilience was conceptualized here also as a *gendered resource* that may perform ‘positive’ and ‘dangerous’ work. It can do work for men by upholding masculinities. Equally, it can work on others by marginalizing or subordinating them. That said, resilience could be turned against the disabled men. For example, the masculine capital gained from performing resilience can enable them to succeed in certain contexts. But, as de Visser et al. (2009) noted, trading masculine capital in other contexts may “be limited because different masculine and non-masculine behaviors are valued differentially by other men” (p. 1055). In contexts were trading masculine capital is limited and unsupported, resilience could therefore move from working for the men to working on or against them. For example, when in a context dominated by a group of men who push the neoliberal health imperative to care personally about ones health, an individual could be severely criticized if they say ‘I don’t need to care about health because I am resilient’. For the group, this latter approach might hold no weight, and thus for the individual in their company hegemonic masculinities would be difficult to uphold. That recognized, as subjects who care first about their health, the men could be seen to deflect any potential criticism from others who hail them to care and rescue their masculinities. Bolstering this, the men did engage in health behaviors like LTPA.

This paper has also made a contribution to our knowledge by theoretically further unpacking part of the process of why some men might take on board an approach to care for their health. Caring for health facilitated an emerging narrative. This desire to care was shaped by the needs of having and being a material body. But, it was also produced through a complex social process of narrative interpellation, habitus, and masculinities. The process of rehabilitation created a new subject who was called upon to take ‘health’ seriously. The men could have passed over
such a call to be this subject, letting it float by in the river of not-for-me. Yet, they did not. Why? In part, the men’s narrative habitus predisposed them to hear stories that called on them to take of their health as those they ought to take on board and be guided by. This though puts hegemonic masculinities at risk. To manage this risk – to uphold masculinities whilst also meeting the call to care - the men artfully reorganized their story and took on board a new claim. That is, I don’t care too much health. The openness of the emergent story told helped provide space for them to take on board this approach and fit it into their understanding of health.

Moreover, in the psychology and sociology of health, what Robertson (2006) and Robertson et al. (2010) named the ‘don’t care/should care’ dichotomy has been established as a discourse for firstly demonstrating hegemonic masculinity and then secondly showing that health matters. This dichotomy is reversed here. For the disabled men, a ‘should care’ approach to health is first storied, and then second ‘but not too much’ stressed. This different way of doing health and gender, identified first here, not only facilitates an emergent narrative. It also enables the men to rescue masculinities in a way that keeps ‘caring about health’ at the forefront of the story they tell rather than relegating it to a secondary position. This move could lead to efforts to engage in health work and healthy behaviors, like LTPA. Of course, such a proposal requires future empirical comparative work. But, given narratives do things on, in, and for people that make a difference, knowing if there are different outcomes in relation to where in the story caring about health is placed (i.e. first or second), and if so what the dynamics of these are, could lead to more meaningful health promotion strategies being crafted. This paper makes a start in this regard by calling attention to a ‘should care/but not too much’ approach for the first time.

In addition to the ‘naming’ of the emergent narrative, several practical usages arise from this research. One is policy makers, health psychologists, sport and exercise scientists, and other health professionals need to target disabled men in ways that interpellate and account for narrative habitus. For example, cognitively a person can know about the health benefits that go with being physically active. Yet, like most other disabled people, they still do not engage in physical
activity. A possible reason for this is that a person’s narrative habitus predisposes them to feel physical activity is not for them (Griffin, 2010). Thus, narratives of this health behavior offered by specific people, groups, or organizations can fail to interpellate; they represent a behavior that tacitly people don’t feel comfortable with, attracted to, worth selecting, and getting caught up in. Certain physical activity narratives offered just don’t taste right.

However, whilst narrative habitus can affect what stories will be heard and passed over as not-for-me, a person’s habitus is not their narrative destiny. As Frank (2010) stated, “habitus can be predisposing, but predisposition is never determination” (p. 58). Given this, what is vital for enhancing the promotion of men’s health or the likelihood of behavior change is opportunities for stories to call and bid successfully for a location within the organization of a person’s narrative habitus, that is, their inner library of stories (Frank, 2010). To aid this – to break through a person’s narrative habitus and find a location within ones library – we can harness the capacity of stories for what Frank (2010) termed narrative ambush. Health professionals can ambush people in contexts like rehabilitation by increasing the narrative resources people have access to, thereby expanding the number of narratives that are allowed to act - to do things for and in people. We can share and amplify stories that inspire people to create new sections in their inner library; stories individuals have not put themselves in a position to hear so that different ways of being a healthy male may be imagined.

To increase possibilities of change, health promotion messages can furthermore be cast themselves as stories. This is warranted for several reasons. As Bruner (2002) argued, people have two complementary modes of thought: the logical-paradigmatic mode (involved with discovering laws and causal relationships) and the narrative mode (involved with constituting human experience, meaning-making, and the social). When research knowledge is translated into public messages, like those encouraging people to do physical activity, they are often done so by using just the logical-paradigmatic mode. To truly promote health change we need however to ‘tap’ not just into this mode, but also the narrative mode of thought by offering stories. This move is
particularly appealing since stories have the capacity to ambush people by attracting and holding their imaginations. A story, unlike a code, guideline, or principle, asks first that the listener imagine (Bruner, 2002; Frank, 2010. It is this imaginative opening that can make stories attractive and ambushing practical, explaining partly why people might be willing to listen to a story and find a location for it in the library of stories, thus expanding narrative habitus.

Given that stories can arouse a person or group’s imagination and open up possibilities for them to imagine different worlds – including their gendered health behaviors like physical activity -, this capacity could be harnessed as part of knowledge translation practices to help change people’s health behavior. For example, on the one hand, messages in the form of stories might be spun which, infused with masculine signifiers/metaphors and images of men taking action, inform disabled men that resilience can be developed through exercise or sport and is about having the discipline and self-control to care for one’s health. Operating as counter-narratives, stories could likewise aim to resist any meaning of resilience as a resource for both legitimizing not needing to care too about health and performing masculinity. They could counter an equation between being masculine and being able to bounce back when faced with health threats or illness. Men too might be storied as proactive, and not simply passively reactive to illness, in terms managing their own health and actively preventing illness. On the other hand, strategies also need to be deployed which challenge the story that caring for health and body-self is feminine, and something one shouldn’t care too much about.

This paper revealed the emergent health narrative and that disabled men can care about doing health work, but not too much. Throughout it was shown that narrative matters: narratives help conduct human life, shaping health behavior, doing things on, in and for disabled men. Also it was proposed that when dealing with health behavior change we should incorporate a focus on narrative. It is hoped this paper increases dialogue on men, disability, LTPA, and health.
References


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