

10 Becoming Disabled Through Sport: Multiple Responses to an Embodied Chaos Narrative

BRETT SMITH AND ANDREW C. SPARKES

Introduction

In recent years we have been eliciting, and concerned with, the life stories of fourteen men who have experienced spinal cord injury (SCI) through playing the contact sport of rugby football union and who now define themselves as disabled. Our concern was partly with what narrative resources are available to them following this embodied traumatic life event. Three main resources were identified. These were the restitution, quest, and chaos narratives as defined by Frank (1995). Our analysis revealed that eleven of the men in our study drew on the restitution narrative. For them, the plot of this narrative has the basic storyline, 'Yesterday I was able-bodied, today I'm disabled, but at some point in the future I'll be able-bodied again.' In contrast, two of the men accessed quest narratives to frame their personal story. These narratives meet suffering head on. They accept impairment and seek to *use* it. Finally, one man told a chaos narrative. The plot of this story imagines life never getting better.

As part of the men's desire, and our ethical responsibility to increase the circulation of these stories and have more of them witnessed, over time we have presented them to various audiences in different contexts. For example, their stories told to us, at particular moments in their lives, have been circulated to sociologists, psychologists, sport and exercise scientists, disability scholars, nurses, medics, and physiotherapists at academic conferences, universities, and through journal publications (eg. Smith and Sparkes, 2002, 2004, 2005; Sparkes and Smith, 2002, 2003, 2005). Furthermore, they have been circulated to, and witnessed by, both disabled and able-bodied people, as well as their families, within the contexts of spinal injury rehabilitation hospitals, sport organisations, and different social settings.

As we have circulated the men's stories, a multiplicity of complex issues has come to our attention. One of these, one that recurred time after time irrespective of the type of story we presented, the audience, or the context, is concerned with people's different *responses* to the *chaos narrative*. That is, rather than the restitution or quest narrative, this story was the one which was singled out and called for response after response. Accordingly, in what follows we, as story analysts (Smith and Sparkes, 2006), seek to make explicit

the multiple responses other people invoke after hearing a chaos narrative as reported by us. Four types of response to chaos are outlined here. These are *breakthrough restitution stories*; *therapy restitution stories*; *social model stories*; and *consolation stories*. With all this in mind, we now turn to the chaos story itself and then consider some of the different responses to it that we have witnessed over the years.

The Chaos Narrative and Jamie

Jamie (a pseudonym) is a working class father of three and a former dedicated rugby player who suffered a spinal cord injury (SCI) at the C2 level through playing this sport. The severity of his spinal trauma is such that he now requires artificial life support and breathes using a ventilator. Jamie has no sensation or movement below the neck. Shortly after the SCI, Jamie's wife divorced him. He is currently unemployed, lives in a new bungalow, his children visit him fortnightly, and he has two female care assistants. With respect to Jamie, what a chaos narrative is like is captured in an interview fragment reconstructed by ourselves below.

Interviewer: How do you feel about life now?

Jamie: Life is not worth living now. I feel nothing. Feel, it's shattering, shattering. The whole thing, just completely shattering. Life has been, it's been beaten, life's been beaten out of me.

Interviewer: I'm, I'm not sure what to say.

Jamie: What is there to say? My life is a mess now. I can't remember when I was happy last. I feel, I feel, dead now. Since the accident, it's like this all the time...Then, then, I, I don't know. My life is over. It is over. Over. I've gone...I may as well be dead. The accident has left me with nothing. No one...Life has, has, stopped. I have no life left in me now. Just darkness. Darkness. I'm worthless. And then, then, life has ended. It's an empty existence...Being disabled, people don't want you. I can't blame them. I can't get into most buildings. I can't see people employing me when I need lots of space and good access. I'd like to see my children more. I can't visit them though...There are too many obstacles. No transport...The pavements are not made for what has happened to me. I can't move in the same places as my children...I'm alone now. Life is over for me...I am alone in this world. Then, then, life won't improve. Nothing to live for. It can only get worse. I, I, I may as well be dead.

With this chaos story that we have presented in mind, what narratives, therefore, did people draw on and give upon hearing it? In other words, what responses, as socially predisposed and/or situated stories, may be invoked

when one encounters a chaos story? What response, from the multiple one's chaos might allow, do people plug into and give?

Multiple Reactions to Chaos

Response 1: Breakthrough Restitution Stories

One common response plugged into and given subsequent to hearing a chaos narrative draws on and is shaped by one strand of the cultural narrative of restitution. This story, like all the other responses, acknowledges that a person needs to move out of chaos. It however promotes returning to being able-bodied when things 'go wrong' and gives prominence to a medical cure through *scientific-technology breakthroughs*. This narrative response thus hopes and anticipates that the disabled person's life before disability will be restored and chaos subsequently beaten via being medically cured. These stories can be summarised as follows: 'Jamie needs to get out of chaos. He can do this by hoping and realising that a cure for spinal cord injury through medical innovation (eg. stem cell surgery) will happen. Indeed, science is advancing and walking is after all only natural. So, with a cure, he can get his old life back, and then he will beat chaos.'

Response 2: Therapy Restitution Stories

Another response drawn on and offered after hearing Jamie's chaos narrative also draws on the restitution narrative. However, unlike the strand of restitution which gives prominence to a medical breakthrough cure, this one privileges *therapy* as the solution to getting out of chaos. Therapy restitution stories tell that a person in chaos is depressed and should have therapeutic treatment to get better. These stories can thus be summarised as follows: 'Jamie needs to get out of chaos. He is definitely depressed and needs to be treated. Indeed, the chaos story is good evidence he is depressed. So, he should have therapy, and then he'll get better.'

Response 3: Social Model Stories

The third response draws on a social model to help understand chaos. The social model holds that disability is the outcome of social barriers that restrict the activities of people with impairments. It's storyline therefore, in contrast to the therapy and breakthrough restitution stories that focus on individual body-mind 'failings', gives prominence to the barriers 'out there' in society that create disability and feelings of chaos. These stories can thus be summarised as follows: 'Jamie needs to get out of chaos. He can do this by realising that the

chaos he is experiencing is not his fault. Society is actually the cause. For example, the barriers 'out there' in society restrict and limit his access to his children. This is disabling. It also makes him feel sad and no doubt sustains the chaos story. What is needed then is more action, such as the removal of social barriers.'

Response 4: Consolation Stories

A fourth response to chaos can be termed *consolation stories*. Again, these stories acknowledge that a person needs to move out of chaos. But, without either being prescriptive or knowing what the future holds, these stories tell that he or she might require consolation from those around him or her to enable them to tell their chaos stories and have them witnessed by other bodies. These stories can thus be summarised as follows: 'Jamie needs to get out of chaos. But, to do this he may well have to tell his chaos story and have people to listen to it. Unfortunately, opportunities to do this seem limited. Indeed, the care and support from those around him to enable him to tell chaos and have it heard appear to be restricted following spinal cord injury. If he is able to tell his chaos story and be listened to, however, then getting out of this narrative and telling another one might happen. Who knows though what this different narrative might be.'

Reflections

Multiple interpretations are available of the responses provided in this chapter. The following reflections are offered that go beyond these with a view to generating discussion rather than providing closure on them, as well as the story of Jamie. In the first instance, we would suggest, the responses given by various people in different contexts to a chaotic narrative, and the potential consequences they might have for disabled men, are shaped by cultural narrative forms or plots. For example, one narrative that shaped people's reactions was the restitution story. Painting with broad strokes, and recognising that we are glossing over nuances between them, the usefulness of the *breakthrough and therapy restitution responses* should not be underestimated. Both can serve particular purposes, such as, generating concrete hope for the future (Smith and Sparkes, 2005).

However, there are a number of potential problems and dilemmas that go with these two strands of restitution that need to be acknowledged. For example, within the restitution response to chaos a reliance on medical science is formed and promoted. This has the potential to subordinate someone like Jamie as individuals to a medicalised view of the world that colonises them as embodied beings. As Paterson and Hughes (2000) argue, therapeutic and

rehabilitative approaches to disability and impairment concentrate on rectifying a perceived mental or physical 'flaw' that hampers an individual's ability to function 'normally'. Thus, the *breakthrough* and *therapy restitution* narrative, and the manner in which they frame the body-self, feeds into dominant notions of SCI that view becoming disabled as a personal tragedy, with disability being defined as an 'individual problem' to be rectified via a therapeutic or breakthrough cure. At the same time, the social origins and conditions that ultimately produce these 'problems' are ignored.

A further potential limitation of the *breakthrough* and *therapy restitution* response noted is that it can do *finalisation* through its *monological* storyline. Finalising a person, according to Frank (2005), means claiming to have the last word, the definitive, finalising word, about who he or she is and what they can become. This occurs in and can be done through a monological narrative that claims to utter the final word about the person(s) who is. What it means to finalise is illustrated, for example, when people respond that someone like Jamie in chaos 'is depressed, *should* have therapy, and then *will* get better.' Thus, rather than offering an unfinalised and dialogic response which claims the future is open and not determined, a breakthrough and therapy restitution response turns into a monologue that finalises the person telling chaos. As Frank argues, to finalise the other person is to foreclose their options to live in a different way and to leave that person hopelessly determined and finished off, as if they were already quite dead.

With respect to the *social model* narrative response, this way of reacting to chaos is a potentially useful resource because its storyline promotes the personal liberation and empowerment of disabled people (Smith and Sparkes, 2005). It also invites collective political action by demanding the removal of social barriers that create disability and help maintain chaos. However, it needs to be acknowledged that there are a number of possible problems and dilemmas that go with this story line. For one, in focusing on barriers out there in society to disability, the experiences and feelings of living in chaos may be ignored or denied (Sparkes and Smith, 2002).

Likewise, the social model narrative response might create a disembodied notion of disability and chaos. As Paterson and Hughes (2000) suggest, the social model of disability proposes an untenable separation between body and culture, impairment and disability, so that the body and all of its experiences eventually disappear, and bodily agency is negated. They note how disability studies in general, with its historical concern to challenge disabling barriers in the 'world outside', draws upon Cartesian dualisms to position the body as a passive, precultural object. Another potential problem is that it can neglect difference connected to ethnicity, gender, and type of impairment. It also may downplay the effects of impairment as well as the part socio-cultural narratives play in disabled people's lives.

With regard to the *consolation* narrative response to chaos, this is useful because it suggests that Jamie's story might need to be told and honoured for him to begin the process of moving chaos into the background of his life. This is an important challenge to meet because as Frank (1995, 2004) reminds us, storytelling can play an important role in repairing narrative wreckage as the self is gradually reclaimed in the act of telling. The consolation narrative is also valuable since it does not finalise him. For example, 'If he is able to tell his chaos story and be listened to, however, then getting out of this narrative and telling another one *might* happen. *Who knows though what this different narrative might be*'. Furthermore, the response highlights the care and support that is needed from those around him to enable him to tell his chaos story and be listened to. All this is particularly important because, according to Frank (2004), consolation is a gift.

Consolation comforts when loss occurs or is inevitable. This comfort may be one person's promise not to abandon another. Consolation may render loss more bearable by inviting some shift in belief about the point of living a life that includes suffering. Thus consolation implies a period of transition: a preparation for a time when the present suffering will have turned. Consolation promises that turning. (2004: 2)

To offer consolation, Frank (2004) emphasises, is an act of generosity, a generosity toward others and toward oneself. Generosity may lie in the grace to welcome those like Jamie who have suffered SCI and live in chaos. It begins in and is renewed through 'dialogue: speaking with someone, not about them; entering a space between I and you, in which we remain other, *alter*, but in which we each offer ourselves to be changed by the other' (Frank, 2004: 126). It also includes speaking *to* them and thinking *with* their stories rather than just *about* them.

Despite the usefulness and importance of this consolation response, it is not though without dilemmas, risks, and potential problems. For example, the chaos narrative is located on Norrick's (2005) upper-bounding side of tellability. Due to its transgressive and frightening nature this is a narrative that people prefer not to hear and find it very difficult to listen to on those occasions when it confronts them. Another reason hearing is difficult, Frank (1995) suggests, is because the 'chaos narrative is probably the most embodied form of story. If chaos stories are told on the edges of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate' (Frank, 1995: 101). Such reasons why chaos might be difficult to listen to have, in turn, implications for getting out of chaos. For instance, what listening and dialogue enables, so the refusal to listen and engage in dialogue can deny. The process of reconstructing selves (Smith and Sparkes, in-press) that dialogue helps make possible can be impeded when

some people refuse to accept others as partners in dialogue. As such, telling, hearing, and honouring chaos stories can be an extremely difficult and risky process for all involved.

As part of our work in-progress, we have aspired to highlight some of the (dis)embodied narrative responses people have given to a chaos story. Clearly, much more needs to be said about these responses, as well as others not highlighted here. We hope that this chapter will act as a sounding board for dialogue and further inquiry into them along with the lived experiences of people who become disabled through sport.

References

- Frank, A. (1995) *The Wounded Storyteller*, Chicago, The University of Chicago Press.
- Frank, A.W. (2004) *The Renewal of Generosity*, Chicago, The University of Chicago Press.
- Frank, A. (2005) What is dialogical research, and why should we do it?, *Qualitative Health Research*, 15, 964-974.
- Norrick, N. (2005) The dark side of tellability, *Narrative Inquiry*, 15(2), 323-343.
- Paterson, K. and Hughes, B. (2000) 'Disabled bodies', in P. Hancock, B. Hughes, E. Jagger, K. Paterson, R. Russell, E. Tulle-Winton and M. Tyler (eds.), *The Body, Culture and Society*, (pp.28-44), Buckingham, UK, Open University Press.
- Smith, B. and Sparkes, A.C. (2002) Men, sport, spinal cord injury, and the construction of coherence: narrative practice in action, *Qualitative Research* 2 (2), 143-171.
- Smith, B. and Sparkes, A.C. (2004) Men, sport, and spinal cord injury: an analysis of metaphors and narrative types, *Disability and Society* 19(6), 509-612.
- Smith, B. and Sparkes, A.C. (2005) Men, sport, spinal cord injury and narratives of hope, *Social Science & Medicine* 61(5), 1095-1105.
- Smith, B. and Sparkes, A.C. (2006) Narrative inquiry in psychology: exploring the tensions within, *Qualitative Research in Psychology*, 3(3), 169-192.
- Smith, B. and Sparkes, A.C. (in-press) Contrasting perspectives on narrating selves and identities: an invitation to dialogue, *Qualitative Research*.
- Sparkes, A.C. and Smith, B. (2002) Sport, spinal cord injury, embodied masculinities and the dilemmas of narrative identity, *Men and Masculinities*, 4(3), 258-285.
- Sparkes, A.C. and Smith, B. (2003) Men, sport, spinal cord injury and narrative time, *Qualitative Research*, 3(3), 295-320.

Sparkes, A.C. and Smith, B. (2005) When narratives matter, *Medical Humanities*, 31, 81-88.

