Exploring multiple responses to a chaos narrative

By

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Abstract

Narratives are performative and do things. These include calling on people for a response. This article explores the responses we have witnessed to a chaos narrative told to us by a disabled man that we then shared with different audiences over time. The following four types of response were identified: depression-therapy restitution stories; breakthrough restitution stories; social model stories; and solace stories. Each kind of response is focused on in detail, and their potentials and limitations are considered. The article does not promote one response over another, or seek the last word on the four responses, as the intention is to generate dialogue rather than to finalise. Future possibilities regarding narrative research and responding to stories are also considered.

Keywords: Disability; chaos; narrative; responses; restitution; social model

Introduction

According to Mattingly (1998), narratives do not merely refer to past experience, but may help create experiences for their audience and move them to respond in certain ways. For her, narratives 'mean to be provocative. They request a different response from the audience than denotative prose' (p. 8). Similarly, Frank (2006) argued that narratives are like actors in that they *do* things that can make a difference in terms of the claims made for what counts in relation to other people. More recently, Martin (2007) noted that, 'Stories are performative: through them we initiate, suggest and call for responses' (p. 54). In such ways therefore, rather than being passive, a narrative is a form of social action and the act of narration is a social activity involving other participants who may provide storied responses to a story heard.

With these points in mind, this article is concerned with narrative and the responses people can give to a certain kind of story. Specifically, we have been privileged to be the recipients of a chaos narrative as told to us by a male (Jamie) who suffered a spinal cord injury through playing sport and became disabled. In turn, we have shared aspects of his kind of story with a range of different audiences over time. In what follows we explore the types of response the people in these audiences have made to the chaos narrative they have heard that, as described by Frank (1995), imagines life never getting better. The four most common responses that we have encountered need to be considered as scripts that cultures make available to its members and should be taken as such. The cultural scripts we identified can be categorised as follows: depression-therapy restitution stories; breakthrough restitution stories; social model stories; and solace stories. We acknowledge that these responses do not encompass all of those we have heard or observed over the years. However, it is beyond the scope of this article to consider *all* of the reactions that have ranged

from highly charged statements to emotionally intense and profound silences. Our aim at this point is to illuminate the most salient verbal responses we have witnessed from active co-tellers/listeners to hearing a chaos narrative with a view to encouraging dialogue and critical reflection. Before providing an analysis of these responses, we first offer a theoretical backdrop and some reasons why we have chosen to focus on the reactions we have received to one particular kind of story.

According to Riessman (2008), 'As all storytellers do, investigators face audiences when they present their analytic stories' (p. 184). These stories, in turn, can move audiences to respond in certain ways. Here, issues of tellership and tellability become important. For Ochs and Capps (2001) tellership and tellability are two of the gradient dimensions of narrative. With regard to the former, it is a social activity which runs from one teller recounting a story to more or less active people who listen to it and become 'co-tellers who respond with reactions, queries, or relevant narrative details' (p. 64). Tellability, as treated by Ochs and Capps, 'is a narrative dimension that varies from rhetorical focus on a highly reportable breech of expectations and its eventual consequences (high tellability) to reporting relatively ordinary events (low tellability)' (p. 76). In this regard, Norrick (2005) proposes a two-sided notion of tellability. That is, one that encompasses the familiar lower-bounding side of this phenomenon as sufficient to warrant listener interest and the generally ignored upper-bounding side where tellability merges into the no longer tellable because they are too personal, too embarrassing, or too frightening.

> Some events bear too little significance (for this teller, this setting, these
> listeners) to reach the lower-bounding threshold of tellability, while others are
> so intimate (so frightening) that they lie outside the range of the tellable in the
> current context. Similarly, one narrative rendering of an event may fail to

bring out its significance (humour, strangeness), and thus fail to reach the threshold of tellability, while another telling might render the event so frightening (intimate) that the story is no longer tellable. Hence, the more strange (salacious, frightening) an event (or narrative rendering of it) is, the more tellable the story becomes, seen from the lower-bounding side, but the less tellable it becomes, seen from the upper-bounding side due to the potential transgressions of taboos. (Norrick, 2005: 327)

Without first being aware of it, in recent years we have become enmeshed in the dynamics of tellability and tellership. This has come about due to our life history research with a small group of men who have suffered spinal cord injury (SCI) and become disabled through playing the sport of rugby union football. These men graciously shared their stories with us. We then proceeded to analyse their stories using various sets of theoretical lenses to explore the ways in which specific kinds of narrative shaped their body-self relationships pre- and post SCI. Having done so, we proceeded to share and disseminate our findings via publications in academic journals (e.g., Smith and Sparkes, 2002, 2004, 2005, 2008; Sparkes and Smith, 2002, 2003, 2005, 2008). We also presented the findings about the lives of these men to different audiences in the UK and overseas via academic conferences and invited talks to sociologists, psychologists, sport and exercise scientists, disability scholars, nurses, medics, and physiotherapists. Students in these disciplines have also received these findings during guest lectures at various universities. Moreover, we have offered our findings with both disabled and able-bodied people, as well as their families and friends, within the contexts of spinal injury rehabilitation units, sport organisations, and different social settings.

As part of the process of offering stories and disseminating research we have become increasingly interested in the reactions audiences give to the kinds of stories told by the disabled men in our study. It has become apparent that although stories of becoming disabled through sport are anxiety provoking in themselves, some stories are preferred over others. Thus, for example, some of these men told stories framed by the restitution narrative as defined by Frank (1995) with its attendant metaphors that include fighting to make a comeback and walk again, notions of concrete hope, and time tenses that conceptualise the future as located in the past and associated with the able-body. In terms of tellership, these are responded to with concern, understanding, and approval in many cases as they fit in with dominant notions of heroic masculinity that call for stoicism and courage in the face of challenges and high levels of motivation to overcome adversity. They are clearly tellable to the audience. Likewise, some of the men in our study told stories framed by what Frank termed the quest narrative. This narrative calls on metaphors associated with a journey of self-discovery, notions of being changed for the better, transcendent hope, and time tenses that link the person to living fully in the immediate present. Again, these are tellable to the audience. They are received and reacted to with approval as a 'positive' way to live with disability.

There is, however, a very different reaction to the story told by one of the men in our study called Jamie (a pseudonym), a divorced father of three children who suffered a SCI at the C2 level while engaged in the contact sport of rugby football union. Here, 'C' denotes thoracic vertebrae, and the '2' indicates the neurological level of damage. The severity of the damage means that Jamie requires artificial life support and breathes using a ventilator. He has a lack of sensation and movement below the neck, and has full-time care. Jamie's story is framed by what Frank (1995)

calls the chaos narrative. This narrative imagines life never getting better. The person is sucked under the undertow of impairment and disability and the disasters that may attend them. Further, when in chaos, there is seemingly no end in sight to living this way. The present is empty and the future appears desolate. Consequently, self and identities fragment, and some dissolve. Life is deemed to be meaningless and devoid of purpose. The following extract from one of the interviews with Jamie provides a flavour of this narrative in action (see also Smith and Sparkes, 2008).

> I used to be happy. Life was good. Now it's over…My life ended when I broke my neck playing rugby. I cannot walk, play rugby, breathe on my own, or see my children when I want. Life is over. It's 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….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 may as well be dead.

When we present Jamie's life to various audiences using selections from his own words as given above, we sense the anxiety, discomfort, and fear it instils in them and their need, at times, to respond to the story. We get a sense that we are relaying a story that due to its content is at Norrick's (2005) upper-bounding side of tellability. Indeed, at times with certain audiences we have often felt that Jamie's story has been very close indeed to the no longer tellable.

Against this backdrop, we became interested in the reactions of different audiences to Jamie's story as passed on by us and we began to document these responses. In what follows we present the four most common responses people plug into (Frank, 2006) and verbally tell. These responses have taken the form of depression-therapy restitution stories; breakthrough restitution stories; social model stories; and solace stories.

Multiple responses to chaos

Response 1: Depression-therapy restitution stories

A common response we have encountered can be termed a depression-therapy restitution story. This can be seen as one strand of the narrative of restitution as described by Frank (1995). Specifically, it states that Jamie needs to move out of chaos since it is a horrible story to live in. It emphasises that a person in chaos is depressed and puts the accent on them needing professional and clinical therapeutic treatment to get better. In this way, the chaos narrative is turned into a treatable condition and a psychologically framed restitution narrative is restored. For this reason, this response was termed a depression-therapy restitution narrative. Accordingly, the plot of this type of restitution narrative we witnessed has the following basic storyline: 'Jamie needs to get out chaos since it is no way to live. It's

not a nice story; it's horrible. Jamie can get out of this narrative though by getting therapy. This is because he is definitely depressed and needs to be treated. So, he should have therapy, and then he will get of chaos and be better.'

The following two stories illustrate the depression-therapy restitution cultural script in action and the ways that people can plug into it as they personally tailor their responses to a chaos narrative.

To me the restitution and quest narratives you showed are positive stories to live by after a spinal injury. I can see why people tell them. They make sense. But it's the chaos narrative that we heard that I want to say something about. My initial response to it was shock, of horror. How could a person live like this? It's a horrible story, and Jamie, he doesn't seem to be getting better. His head is really messed up. He needs help fast. It's as clear as day he's depressed, and he needs therapy now. I tell you, this guy should see a therapist. I worry that if he doesn't he'll be living this nightmare for a long, long time. He needs therapy, and then he'll be better. (female occupational therapist – taken from conference fieldnotes)

I don't have anything to say anything about the two stories you showed, the restitution and quest narratives, as they seem fine. It's Jamie's story that hit me. It's awful; it's a dreadful way to live, and yes, he's still alive, but it's not really an existence. I don't know how he gets by. My reaction is that this person needs help. And the more I think about it, the more I feel this person really needs help and to move past this chaotic state. He's struggling badly with his disability. He's obviously depressed, definitely depressed, and he isn't coping well with everything that has happened. If he's got any real

chance of putting this chaos narrative behind him, and if he's to get better, he should see a good therapist. He needs to see one now. (male psychology researcher – taken from a tape recorded university invited talk)

Response 2: Breakthrough restitution stories

Another response we have encountered can be termed a breakthrough restitution narrative. This story acknowledges that Jamie needs to move out of chaos. It is also similar to the depression-therapy restitution response in that it redefines chaos as a treatable condition, thereby turning chaos narratives into restitution narratives. However, rather than placing emphasis on psychological therapy, it puts the accent on a cure that will be found through a bio-technological breakthrough such as stem cell surgery. Here, a disabled person's life before disability is seen as one that can be and will be restored via stem cell surgery. As a consequence, the power and threat of the chaos narrative is defeated as the normative able body is restored and concrete hope (Smith and Sparkes, 2005) is instilled. For these reasons that revolve around bio-technology, a breakthrough response is distinguished from the depression-therapeutic response, and can be seen as a different strand of restitution. This is also why the restitution narrative as described by Frank (1995) is split here into two strands. Thus, the plot of the breakthrough restitution story has the following basic storyline: 'Jamie needs to get out chaos since it is no way to live. It's not a nice story; it's horrible. Jamie can get out of this narrative though by hoping and realising that a cure for spinal cord injury through stem cell surgery will happen soon. In fact, disabled people are successfully undergoing stem cell treatment right now. So, he should be optimistic and believe that he will be cured and then he will beat chaos.'

The following two stories provide a flavour of this breakthrough restitution narrativein action.

Out of the three stories you've presented, I think Jamie's story is the key one. At least it is for me. This person is in real trouble. If I'm honest, I couldn't stomach his words. If I could, I'd have left the room. It's a shit way to live and he needs to move on, get another story. He needs to believe that he won't be like this forever, and battle on. He needs hope, and belief in the medical system. He needs to believe that his injury can be reversed and that the stem cell treatments that are being developed right now will cure him. Treatments are happening now. We know this. Disabled people are having stem cell surgery, and we're seeing successes. If Jamie could see this, and go for surgery, then he'd get better and get out of chaos. He needs to realise that stem cells treatments are possible and be positive about this cure. The only way I can see him beating chaos and being happy again is by getting his old life back this way. (male sociology PhD student – taken from a tape recorded invited university talk)

When you told the chaos story from Jamie, I was thinking 'what the hell is this. Stop, it's not what I want to hear at the end of my day. It a terrible story and Jamie is a mess. It's no way to live.' I still feel the same, and clearly something needs to be done here. Jamie needs to move on and put this horrible story behind him. There is a way. He needs to see there's hope for him. He needs to realise, like Christopher Reeve, the guy who played Superman, that there is hope in stem cell surgery. If he focused his energy on getting this surgery he can put chaos to bed. In fact, there are reports that disabled people

are successfully undergoing stem cell treatment right now. So I think he

should be positive that he'll beat chaos. He should go for stem cell surgery and

then he'll move on (female physiotherapist – taken from conference

fieldnotes)

Response 3: Social model stories

A third response we have encountered to Jamie's chaos narrative can be termed a

social model narrative. Like the previous two responses, it acknowledges that a person

needs to move out of chaos since it is horrible to live by. Yet, rather that seeing

disability and chaos as a product of individual mind or a bodily 'failing' that can be

cured through medical practices as restitution stories do, this response draws on the

basic principles of the social model (Oliver, 1996; Thomas, 2007). That is, it claims

that disability and living in chaos is the result of barriers 'out there' in society.

Accordingly, the plot of social model stories has the following basic storyline: 'Jamie

needs to get out chaos since it is no way to live. It's not a nice story; it's horrible. He

can get out of this narrative though 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 and keeps him in

chaos. What is needed then is the removal of social barriers. Removing these will help

Jamie out of the chaos story that society creates and sustains.'

The following two stories exemplify the social model script that can be

plugged into and individually fashioned to respond to chaos narratives.

Out of all the stories we've heard today, its Jamie's that I feel compelled to

say something about. When I heard it I felt angry, sad, and lost. It really upset

me, perhaps because it's such a horrific tale and because Jamie is still living in

it. It's not a way to exist. He obviously needs get out of it and tell a different story. But how will he do this is the question. I think the social model offers the answer here. Jamie is stuck in chaos because of the socio-structures that disable him and which leave him struggling to see his children, which he clearly loves and misses. We need to continue with political and social action. Jamie needs more opportunities to work, and better access so he can see his children. You see, it's not Jamie that is the problem here. It's society. Removing the social barriers will mean that Jamie can get on with his life, and move out of chaos, rather than being stuck in this way of living. (female disability / sociology researcher – taken from conference fieldnotes)

I consider myself to be a reasonably well rounded person who's heard lots of stories from disabled people – some good, some bad. But I must say, Jamie's chaos story really got to me. I'm not sure why. I know I didn't like it and it's not a nice way for Jamie to live. I wouldn't wish that story on anyone. But it's the social barriers that keep him in this state is what matters here. They need taking away or improving if Jamie is to get out of chaos. Getting rid of barriers is the key for Jamie to move on and escape chaos (male psychology researcher – taken from a tape recorded invited university talk)

Response 4: Solace stories

A fourth response we have encountered may be termed solace stories. Once again, these acknowledge that a person needs to move out of chaos and that it's no way to live post-SCI. But, unlike the others, it claims that to help move out of chaos the individual might need to tell their story, and vitally, have it listened to by friends,

family, carers, and other disabled people. As part of this listening, these people have to actively enter into Jamie's world, empathise, and know what he is going through. Thus, the plot of solace stories has the following basic storyline: 'Jamie needs to get out chaos since it is no way to live. It's not a nice story; it's horrible. He could get out of this narrative though by telling his story, and importantly having his friends, family, carers, and other disabled people listen to it within his everyday life. As part of listening, people should empathise by imagining placing themselves in Jamie's shoes. They need to get inside his story, know how he really feels, and empathise. That's what I would want. If this can be done, then getting out of this chaos narrative and telling another story might happen.'

The following two stories illustrate the solace narrative script that listeners may plug into and personalise to respond to chaos narratives.

> Out of all the stories you presented, what grabbed me in your talk was the chaos story. It was such a sad one. He shouldn't still be living like this. He really needs help in my view, and needs to talk. What he needs is someone to listen to him. I don't mean a therapist here. He's crying out for someone, a friend or someone on an everyday level, to listen to him, and that's what I'd want. I think if people around him were more empathic, if they really empathised and imagined being in his state of mind, in his situation, they would understand his pain. They'd know how he really feels and that would help. They'd be able to listen, and that might help him get out of chaos. He needs to get the awful mess that he's going through off his chest and needs people to listen him. (male medical student – taken from fieldnotes written at a invited university talk)

I'd like to say something about the chaos narrative. The other two kinds of stories you mentioned I've come across, and can appreciate as positive ways of thinking. Jamie's chaos story is a different matter though. It's a terrible tale. I think this person needs some serious help otherwise he'll end up killing himself. He needs to talk to others around him. He needs time to talk and for people close by to pin their ears back. They really need to listen to him and imagine being in his shoes. If I were in his situation, I wouldn't want people to leave me alone each day. I'd want people to listen and speak with me, identify with what I'm going through, and really get in my head to understand what was happening, what the hell I was living through. If they could do all that, then people would listen. They'd understand better. So what I'm saying is that if Jamie is to live a better life and get out of the misery he's in, he needs people to listen to him and empathise. That's the key. (female physiotherapist researcher – taken from a tape recorded conference talk)

Some Reflections

The responses we have encountered from different audiences to a chaos narrative that exists on the upper boundary of tellability can be interpreted in a number of ways. As such, the following reflections are offered with a view to generating dialogue rather than providing the last final word on these responses (Frank, 2004). In the first instance, drawing on Frank (2006) we suggest that these responses are potential actors. That is, they *do* things which can make a difference. They do things which claim, explicitly or implicitly, to tell *what counts* in both *supportive* and *contesting* ways. With regard to being supportive, all responses claim that chaos is a 'horrible' and not 'nice' story to live in and by. Thus, every response performs an evaluative or

value claim that supports each other as to what counts as a 'horrific' story and 'good' or 'bad' way to live following SCI. The four responses also support each other inasmuch as they all claim that given the horrors of living in chaos then moving out of it is to be desired. What counts is getting out of chaos.

Yet, whilst all responses offer some support to each other, they also do things by making *contesting* value claims as to what counts as getting out of chaos. With respect to depression-therapeutic restitution responses, chaotic stories are heard as documenting depression and the person is defined as depressed. Thus, with a strong nod toward a mind-body dualism, what counts to get out of chaos is professional and clinical therapeutic intervention on the psychology or 'mind' of the person so that they can overcome and escape from their chaotic body. Likewise, breakthrough restitution responses do something by reaffirming the importance of the rubric of medicine to move out of chaos. However, what counts for this strand of restitution is not psychological therapy, but the physical intervention and restorative effects (hopefully) of stem cell surgery. From this perspective, a bio-technological breakthrough is what is needed to release Jamie from the psychic chaos that his material and disabled body inflicts upon him by returning him to his former able bodied state of being along with the normative narratives that attend this restored body-self.

In contrast to these two strands of restitution, social model narrative responses prioritise that what counts to get out of chaos is the removal of barriers 'out there' in society because these act to oppress and disable people thereby creating and sustaining the conditions in which chaos is produced. It makes claims for socio-structural change rather than medicalised interventions on individual bodies like stem

cell surgery or clinical therapy. It thus differs from and contests the restitution responses in terms of what counts to move out of chaos.

Finally, and adding another layer of contestation, what might count as getting out of embodied chaos for *solace responses* is a communing body that listens and shares its stories in everyday contexts. Thus, similar to what Frank (1995) terms a communicative body, what is needed and valued by this response is listening to others, acting for them, and connecting in a dyadic fashion over time.

Therefore, all responses, all types of tellership, agree that chaos is no way to live and is a horrible story that one needs to move out of, but each one suggests a different way of how to get out of it. Although some claims support those made in other responses, other claims contest what other responses say count. In this regard, each response potentially competes for attention. In terms of what counts as getting out of chaotic bodies each cultural script may also *do* things by upholding and perpetuating a range of potential dilemmas and problems.

Depression-therapy narrative and the breakthrough narrative response: Potential problems

With regard to the depression-therapy narrative response and the breakthrough narrative response, at one level, both may sustain a number of similar problems and dilemmas. For example, as Frank (1995) points out, 'The first limitation of restitution stories is the obvious but often neglected limitation of the modernist deconstruction of mortality: when it doesn't work any longer, there is no other story to fall back on. Restitution stories no longer work when the person is dying or when impairment will remain chronic' (p. 94). Thus, problems may arise when the disabled person does not find restitution because the body-self is not fixed or cured through a type of therapy or bio-technological intervention.

Furthermore, the therapy and breakthrough restitution responses may help maintain the great *social pressure* to tell restitution stories. As Murphy (1990) and Frank (2007) suggest, the social pressure to tell restitution narratives, coupled with the *emotional work* (Hochschild, 1983) that often goes with this pressure to tell, can be draining and oppressive to disabled people and their families, since it often requires the denial of the realities of their lives. Likewise, the depression-therapy and breakthrough restitution responses may reproduce the social pressure to control our bodies and be responsible for our distance to or from normative body ideals. This can also be especially problematic for disabled people. As Wendell (1996) notes, in a society that idealises a specific and narrowly defined body, people who approximate the ideal, and those whose bodies are seemingly out of control, like those of many disabled people, face various forms of stigmatisation. In short, she argues, they become 'devalued people because of their devalued bodies. Moreover, they are constant reminders to the temporarily 'normal' of the rejected body—of what the 'normal' are trying to avoid, forget, and ignore' (p. 91).

A further potential limitation of the two strands of restitution responses is that they treat disability, implicitly or explicitly, as a tragedy, a bodily *deficit*, and a *flawed* existence that one *should* overcome with the services of bio-technology, rehabilitation, or certain kinds of therapy. These responses risk finalising the individual and producing a *monologue* (Bakhtin, 1984). With respect to the depression-therapy restitution narrative, what it means to finalise and speak in a monological voice is illustrated when people respond to chaos by saying that the individual in chaos (i.e. Jamie) '*is definitely* depressed and *needs* to be treated. So, he *should* have therapy, and then he *will* get of chaos and be better.' restitution responses informed by bio-technological interventions, monological finalisations are uttered

when they claim that a person can get out of chaos by 'hoping and realising that a cure for spinal cord injury through stem cell surgery *will* happen soon. In fact, disabled people are successfully undergoing stem cell treatment right now. So, he [Jamie] *should* be optimistic and believe that he *will* be cured and then he *will* beat chaos.' Such responses, therefore, carry a moral imperative for the person in chaos to display the appropriate attitude to overcome chaos by giving themselves over to the will of 'expert' others who have the professional knowledge to solve the 'problem'.

Monological finalisations, like those described above, can be problematic according to Frank (2004) because they encourage us to think *about* rather than *with* stories. Further, suggests Frank (2005), because it has the final last word and the definitive declaration, a finalised and monological voice claims authority and privileged knowledge. As a result, monological finalisation can operate to silence other voices. It can foreclose a person's options to live in a different way and might, suggests Frank, leave that person hopelessly determined and finished off. The individual may be left feeling that there is nothing more in them, nothing more to be said about them, and there are no other prospects. Thus, as Frank writes, not only is this an empirically inadequate description of the human condition, but 'all that is unethical begins and ends when one human being claims to determine all that another is and can be' (p. 966).

Both depression-therapy and medical-technology breakthrough restitution narrative responses hold limitations and dilemmas that are similar. However, there are also some subtle differences between them. This is another reason why the restitution narrative is divided into two strands. For example*,* depression-therapy narratives risk promoting that a person needs to be dragged out of chaos and rushed on. As Frank (1995) suggests, whilst those living in chaos certainly need help, the immediate

impulse of most would-be helpers is 'first to drag the teller out of this story, that dragging called some version of "therapy". Getting out of chaos is to be desired, but people can only be helped out when those who care are first willing to become witnesses to the story' (p. 110). Thus, for him, one of the *worst* things people can do to someone in the chaos story is rush or push them to move on.

> Moving on is desirable; chaos is the pit of narrative wreckage. But attempting to push the person out of this wreckage only denies what is being experienced and compounds the chaos. The anxiety that the chaos story provokes in others leads to the standard clinical dismissal of chaos stories as documenting "depression." When chaos is thus defined as a treatable condition, the restitution narrative is restored. Clinical staff can once again be comfortably in control: the chaos can be dismissed as the patient's personal malfunction. That reality is classified as either amenable or resistant to treatment: in either case, it no longer represents an existential threat. (Frank, 1995: 110)

With respect to the medical breakthrough narrative response, this can be problematic since it may reproduce and perpetuate an assumption that being able-bodied and walking is the 'natural' and 'right' way to exist. However, walking is not simply a biological, locomotor act. It is also infused with meaning and is therefore also a socio-cultural act. As Oliver (1996) argues, to be able to 'stand on one's own two feet' is of more than figurative significance. In Western societies, verticality is often related to independence, control, sexual prowess, and being able to work. Not being able to walk is correspondingly assumed to mean that an individual is not physically attractive, and has lost independence, control, ability to work, and so on. For Oliver, it also can lead to the supposition that being disabled and unable to walk must *always* be a tragedy and result in personal malfunction. However, as many

disabled people testify, this is far from the case. For some people, given the choice, walking might not be desired since being disabled is a positive experience and body-self affirming (Smith and Sparkes, 2005; Swain and French, 2000).

Furthermore, by drawing on the breakthrough restitution narrative and its cure agenda to help respond to chaos, there is the danger of perpetuating and calling on others to collude in the major practical problem that new bio-technological research findings are often associated with hyperbole, fixing the story on one desired end-state, and raising expectations, which do not happen or then translate into benefits (Wainwright, Williams, Michael, Farsides, and Cribb, 2006). This is particularly concerning given society is not awash with different narratives on which to fit ones 'own' experiences into or build valued forms of embodiment and alternative identities following SCI. For example, the immense social machinery of the media often promotes a cure agenda tied to the hope that stem cells therapy might bring for 'curing' disability and returning a spinal cord injured person to an able-bodied state of being (e.g., see Goggin and Newell, 2004). Yet in doing so, the canonical narrative of disability as a tragedy is maintained. Further, in promoting a 'cure' for SCI, rarely are different narratives shared or important questions asked. For example, how does disability figure in contemporary society along with who do we count as members of our moral community, and whom do we not count and then exclude? Therefore, important questions are glossed over. We are also left with a small and impoverished pool of narratives to draw on. This may be especially problematic when the dominant cultural scripts available do not fit a person's 'own' experiences, are out of step with their life, or fail to take care of them. That is, by failing to share multiple narratives, disabled and able-bodied people's access to narrative resources for storying their lives in different ways if they wished and if circumstances changed can be limited.

Moreover, both able-bodied and disabled abilities to engage in dialogue with others are constrained.

Social model response: Potential problems

One potential problem and limitation of a social model response in certain circumstances is that, like the two strands of restitution, it can uphold a measure of monological finalisation (Smith, 2008). That is, it prescribes and concludes with some certainty that for Jamie to get out of chaos, 'What *is* needed then is the removal of social barriers. Removing these *will* help him out of this chaos story society creates and sustains.' Not only are there potential problems with such words as they risk finalising a person, but these words also risk promoting a barrier-free utopia that might be incompatibility with some disabled people's needs. Further, we should not forget that barrier removal often does not happen over night and can be difficult to achieve because of nature, resource constraints, and practical resources (Shakespeare, 2006).

Another possible problem with the social model response to chaos is that it risks depicting disabled people as a homogeneous social group who speak with one voice. However, as Thomas (2007) reminds us, disabled people do not constitute such a 'social group. Rather, experiences of disablism and living with impairment are understood to be bound up with other cultural markers of social 'difference': gender, 'race', sexuality, age and class' (p. 70). Thus, an empirically inaccurate depiction is risked by the social model response to chaos if it depicts disabled as homogeneous social group. There is also the risk of negating the realities of those who do not see themselves as part of the collective disability rights movement and pushing into the

margins issues of gender, race, age, and class. In so doing, diversity and difference may be overlooked.

A further concern with the social model, and the way drawing on it to respond to a chaos narrative may be problematic or over simplistic, relates to the body. The social model as outlined by Oliver (1996) has a tendency to marginalise the impaired body and people's personal experiences of living in, as, and through a disabled body (Hughes and Paterson, 1997; Smith and Sparkes, 2008; Thomas, 2007). As Oliver put it, 'disability is wholly and exclusively social…disablement is nothing to do with the body' (pp. 41-42). One reason given for this disregard is that to dwell on bodily impairment, or the lived body, is a diversion from the main political struggle of ending collective oppression through dismantling socio-structural barriers. However, pushing the impaired body into the margins and disregarding social theorising 'from' lived bodies, as Williams and Bendelow (1998) argue is problematic. Likewise, as Thomas (2007) suggests, by ignoring the body we risk overlooking the 'impaired body' as simultaneously biological and social. Likewise, the effects of impairment and the psycho-emotional dimensions of disability are neglected. Moreover, Hughes and Paterson (1997) argue that, despite its success, part of the problem of the social model lies with the displacement, if not complete effacement, of the lived body. This is particularly so in view of the following:

> Disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning...Most importantly, the (impaired) body is not just experienced: It is also the very basis of experience...Disability is, therefore, experienced from the perspective of impairment. One's body is one's window on the world. (Hughes and Paterson, 1997: 334-335)

Accordingly, by focusing exclusively on removing barriers 'out there' in society to help a person get out of chaos, social model responses risk overlooking the chaotic body, its lived experiences, stories, psycho-emotional dimensions, and the socio-biological conditions that shape and constrain it.

Solace response: Potential problems

Finally, it needs to be acknowledged that there are also potential dilemmas, risks, and problems with the *solace narrative*. For example, this response suggests that telling a chaos story to oneself is a beginning, but for that story to have its fullest effect and for the person telling it to flourish and move on, someone else needs to *listen*. Yet, listening to the chaos narrative can be an extremely difficult, risky, complex, delicate, and precarious process for all involved. As Frank (1995) acknowledges, this kind of narrative is anxiety provoking, threatening, and difficult to hear partly because it lacks any coherent sequence or plot. As such, the teller is not understood as telling a 'proper story'. Likewise, listening to chaos can be difficult because it constitutes a risk to our ontological security (Giddens, 1991). Moreover, notes Charmaz (1999), telling and listening to sad tales like chaos may captivate audiences, but they 'may wear out sympathetic audiences' (p. 373).

Furthermore, the unacceptability of the chaos narrative to listeners is closely linked to the issue of desire. As Mattingly (1998) suggests:

> The essential place of desire in a narrative model is particularly striking when we realise not only that the story hero but even the story listener is drawn to desire certain story outcomes and fear others…When a story is told, if that storytelling is successful, it creates in the listener a hope that some endings (generally the endings the hero also cares about) will transpire … We hope for certain ending; others we dread. We act in order to bring certain endings

about, to realise certain futures, and to avoid others. (Mattingly, 1998: 93)

Given the desire for certain kinds of endings to stories, the implications of the chaos narrative can instigate in the listener what Marcus and Nurius (1986) term a *feared self*. This is a type of possible or imagined self that one does not desire to become as it is defined as an alien 'other'. This feared self acts as a motivator, so that the individual takes action to avoid the possible body-self they fear and are afraid to be. As a consequence, certain narratives are foregrounded and celebrated while others are marginalised and silenced. Indeed, as Hughes (2007) notes, most often non-disabled people do not desire a 'bit of the disabled other', including their stories of chaos. Thus, for him, 'if we rip open the psychological nest of disabling culture to examine the interstices of intersubjectivity between disabled and non-disabled actors we are more likely to discover fear and anxiety than the playful admiration and aesthetic mimicry' (p. 680). In highlighting such problems, however, we do not deny that listening, and listening differently, is not possible or vital as a way to help get out of chaos. The point we make is that in the responses we have witnessed, the difficulties of listening are rarely acknowledged, raised, or discussed.

In addition to the problems of listening, even if one is well-intentioned, by suggesting that to help get out of chaos listeners 'should empathise by imagining placing themselves in Jamie's shoes…get inside his story, know how he really feels, and empathise', a solace response risks projecting onto the other ones own beliefs and attitudes, values and priorities, fears and hopes, and desires and aversions (Mackenzie and Scully, 2007). Equally, we may misrepresent the views, needs and concerns of others, and arrive at moral judgments that are inappropriate and/or paternalistic. Another problem and danger in thinking that one should empathise by placing oneself imaginatively in another's body, getting inside them and their story, and knowing how

they *really* feel, is that this can violate and infringe the alterity of the other person (Smith, 2008). Alterity, as described by Levinas (2001), can be characterised as a person's *otherness* that precedes any attributes. The other *is* other. So just as the other is fundamentally *not* me, fundamentally irreducible *to* me, so too is his or her chaotic body narrative. Therefore, any attempt to get inside the other's chaos and to place oneself in another's body is problematic and elusive as it risks violating what makes them other. This may be particularly dangerous as it can inflict symbolic violence (Bourdieu, 1998; Frank, 1994).

According to Frank (2004), 'to infringe on the other person's alterity—their otherness that precedes any attributes—is to commit violence against the other. Symbolic violence comprises the often subtle ways that alterity is challenged and violated' (p. 115). A further way a person may commit symbolic violence in relation to solace responses is by claiming that 'you are as I am', and 'I *know* how you feel'. Here, notes Frank, empathy can easily turn into projection, or sometimes introjection, which involves the illusion that one can truly put oneself in the place of another person and merge with them. Indeed, it denies difference between self and other, and in so doing one denies the other, and their alterity. Alterity, it should be underscored, is not opposed to empathy. But, as Frank reminds us, empathy as an end in itself can be dangerous to alterity. Empathy tends toward unification: for example projecting my fears and what would make me feel better onto you, or my merging with another's chaos. Alterity is the opposite of merging with others and thinking that one can put their self in the place of others. Thus, for Frank (2005), 'Seeking to enter the other's life seems generous, but it risks losing the mutual otherness that sustains the boundary between persons and thus sustains a fundamental condition for dialogue—that it be between people who remain mutually other' (p. 295).

Rejecting all responses?

Set against this critique of the four responses we have encountered to a chaos narrative, we want to guard against this being interpreted as a simplistic rejection of them all. Likewise, we resist the impulse to state that one response is better than the others, or that one is only way to respond to chaos. This is because prescribing *this* is the right or wrong way to respond to chaos, and offering the assurance of knowing what response a person *should* give when faced with chaos, would risk monological finalisation (Frank, 2004). Another reason is that the teller of a chaos story cannot control how the story acts on and for the audience. Thus, what the narrative evokes and how an audience interprets it are unpredictable. As Frank (2006) argues, stories are actors that do things that can make a difference and claim what counts.

> Yet like all actors, stories make a difference in relation to other actors, and exactly what difference they make will never be predicted … Stories make themselves available to consciousness because they support many view points; the same story makes a different point to different listeners. As actors in relation to other actors, stories are always a bit out of control. (Frank, 2006: 423)

Accordingly, in highlighting these different responses to the chaos story we do not intend to suggest that one response is more legitimate or 'better' than another. Rather, these varied responses are an example of how, as Frank (2006) suggests, stories affect people in different ways that cannot be controlled or totally predicted by their tellers. Likewise, for Ochs and Capps (2001), in terms of tellership, 'the active participation of conversational partners means that no one holds control over the direction a narrative may take' (pp. 54-55). Given these points, a degree of uncertainty over how and in what ways a person or group responds to a chaos story is

only to be expected. Researchers, health professionals, and disabled people, may need then to prepare themselves to acknowledge that audiences will read the chaos stories they produce or tell in potentially different ways. Without claiming that 'anything goes' or that we cannot challenge responses, they might learn to live 'with uncertainty, with the absence of final vindications, with the hope of solutions in the form of epistemological guarantees' (Schwandt, 1996: 59).

Another reason why we resist rejecting all responses or proposing which response is the 'best' is that each one in certain circumstances may be useful, plausible, and of value to a person or community. For example, whilst recognising that there is a dazzling array of therapies now available, offering therapy restitution responses to a chaotic story might open up and legitimate for the person in chaos the possibility of engaging in therapeutic practices. In certain kinds of narrative therapy, for instance, there may then be the possibility of telling a new story and moving chaos into the background of one's life (see Angus and McLeod, 2004). Further, along with a depression-therapy response, breakthrough restitution responses have the potential to offer people concrete hope which may help to palliate or assuage misery, construct a sense of continuity after SCI, and create a plot structure in which having this kind of hope means having a future (Mattingly, 1998; Smith and Sparkes, 2005). Moreover, for Shakespeare (2006), if stem cells therapies materialise, and if they are safe and effective, some disabled people may benefit and their quality of life could improve. As such, we should not simply discount or undervalue them.

It is also important not to throw out or underestimate the potential value of the social model response. For example, its storyline promotes a political strategy in which the social practices that oppress disable people are brought under the spotlight. Equally, it invites political action by demanding the removal of social barriers that

help create disability, oppress disabled people, and may help maintain chaos (Smith and Sparkes, 2008). It has the potential likewise to help redress and challenge the way in which research evidence related to a medical cure is often sanitised, de-contextualised, and/or distorted when presented by the media. The social model response storyline might also have a revelatory, liberatory, and transformative impact on disabled people by making available, and legitimising, different ways of living as a disabled person (Swain and French, 2000). For instance, in suggesting that social barriers help create and sustain disability and chaos, it invites people to feel that they and their impaired body aren't at fault. Rather, it is society which is at fault and needs to change. Thus, a social model response may engender self-confidence and pride, rather than guilty knowledge and shame.

The solace narrative response is also a potentially useful resource given that, unlike the others, it does not seemingly attempt to push the person out of chaos and deny what is being experienced. Indeed, it claims that to possibility get out of chaos the individual might need to tell their story and have it listened to. Listening to chaos is a vital challenge to meet because, as Frank (1995) argues, if the chaos story is not listened to and hence honoured, the world in all its possibilities is denied. For him, to deny the chaos story and not listen to it is to deny the person telling this story which means that they cannot be cared for. Moreover, for Frank, people can be helped out when those who care are willing to listen, become witnesses to the story, and stay with it. As he says, getting out of an old story necessitates telling a new one, but the 'chaos narrative requires a listener who is prepared to hear it as testimony' (p. 137). This is particularly important, according to Frank (2004), since to listen and offer witness may be an act of generosity, a generosity toward others and toward oneself.

A further reason why we resist simply rejecting all responses and refuse to

specify which response is the 'best' or 'right' one to give is autobiographical in nature. Ever since encountering Jamie, rather than giving one single response to his story, *all* responses at particular times and under certain circumstances have been told, felt within our bodies, and performed by us. We have in our heads and hearts oscillated between each different response, changing across and shifting among them. Cognitively and emotionally we have at various times been caught up in every one, and what counts to get out of chaos has shifted. Given this, there may now be the expectation to hear that we have settled on one response. But, for the time being at least, we remain caught up in moving between them. Our uncertainties and dilemmas remain as we continue the process of travelling with Jamie's stories of chaos. We also continue to wonder, if none of these responses is wholly adequate (though each has its rationale and strengths), what can be said? Or are we left like Conrad's Kurtz: 'the horror'. Maybe, dark as that is, that's how it is?[1]

Closing thoughts

In this article, we have examined four different responses to a chaos story. None of the responses we have focused on are better than the others when confronted by a chaos narrative and we have no wish to privilege or elevate one response over another. Rather, via a critique of these responses we have tried to drawn attention to the complex assumptions that inform their construction as well as to their possible impact on both the teller and listener. To develop this project future research will need to consider a number of issues. For example, like many narrative analyses, we have relied heavily in this article on people's verbal responses[2]. As a consequence, what is *not* said is absent. Yet, what is not expressed is important for developing our understanding of responses. Indeed, our ability to verbally articulate our felt responses to others can be extremely difficult. Sometimes words are inadequate to get across the

raw emotional reactions that chaos can elicit in us. In such circumstances, our responses to a chaos narrative may reside beyond words to be left contained in profound, if uneasy silences. Whilst not easy, future work, therefore, needs to attend to not just what we say verbally, but also what we do *not* say, to the multiple meanings of silence. As part of this venture, there is also a need to consider the various ways in which the body via its movement, postures, and gestures is used to communicate meanings and inform responses that, even though they are beyond words, are central to the manifestation of the telling and listening self (Kontos, 2005). One possible way to help explore this is through the use of videotaping digital technology and the subsequent microanalysis of frame-to-frame records of embodied action (Hydén and Orulv, in press; Sarbin, 2001).

Furthermore, our analysis of responses to chaos presented here tells us little about how they are produced or mediated by social contexts. One way to explore how different responses are produced is to turn our analytic attention to what Gubrium and Holstein (2008) call 'narrative work' (see also Zilber, Tuval-Mashiach, and Lieblich, 2008 for a complimentary way). That is, to focus on the social organisation and interactional dynamics (e.g. performance and collaboration) through which narratives and people's responses to them are constructed, communicated, and sustained or reconfigured. Likewise, to fully develop our analysis and typology of responses future research is needed that focuses on people's narrative environments. These are the contexts (e.g. close relationships and places) within which the work of storytelling and responding to narratives get done and is mediated (Gubrium and Holstein, 2008; Hydén and Orulv, in press; Phoenix and Howe, in-press; Randell and McKim, 2008). For instance, who makes up the audience and their relationship to the storyteller is likely to influence how they respond to the story being told. Here, for example, an

audience made up of close friends might produce different responses to an audience made up of more 'detached' health professionals due to the length and quality of time that they had shared with the person in chaos and the extent to which it had changed both of their lives. In this sense, it could be suggested that our typology of responses to Jamie's chaos story might be more appropriate to a 'stranger' context rather than to a context involving loved ones or close friends who have greater emotional involvement in the story being told. Of course, similar responses can be given in both close and distant contexts. Moreover, it is possible for the same individual to give different responses when they become members of different audiences. Again, these are complex processes that require further investigation.

Finally, and most importantly, in terms of responses we have considered in this article, there is one voice that is conspicuous by its absence. That is, the voice of Jamie. How does he respond to us, to our stories of him, to the responses of others to his story? What do these responses mean to him? Do these responses help take care of him? Exploring such questions, and speaking with Jamie further (if he so wishes), is clearly important. That said, there might be dilemmas and risks involved. For example, whilst it could be helpful to readers to have a view of what he says and does in light of these responses, how helpful though might this be for Jamie himself? Could speaking more with Jamie in the near future and sharing people's responses to his story be useful and liberating for him in some ways, and/or might this process be harmful.

Clearly, then, there are an array of on-going considerations that need further reflection, and much work remains to be done. None of this is easy. However, staying with all this is not impossible. For us, in different sets of circumstance and for certain purposes, staying with stories and exploring the varied responses people give to them

may be worth it because the ways in which people respond to stories can effect and affect others. Our responses can reverberate. They may act on and for us, shaping, constraining, and/or enabling our lives and the stories we might tell. We hope this article provides a resource that encourages people who inhabit and constitute various audiences to critically reflect on how they respond to different narratives depending on the context in which they find themselves. As part of this process, there may be a possibility to not only enhance their own story listening and telling experiences, but also the experiences of others, as they embody and respond to narratives throughout their lives.

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[1] Thank you to the reviewer for this reference to Conrad's 'Heart of darkness'.
[2] Thank you to the reviewer for pointing this out to us.