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## Resilience in people with spinal cord injury: a narrative approach

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Resilience in People with Spinal Cord Injury: A Narrative Approach

by

Joanna Kirkby

A Doctoral Thesis

Submitted in partial fulfilment of the requirements for the  
Award of Doctor of Philosophy of Loughborough University

2016

For my Mum and Dad

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## ABSTRACT

This PhD thesis explores the phenomenon of resilience in people with spinal cord injury (SCI). The purpose of this research is to understand how resilience is experienced and given meaning in people with SCI, as well how resilience is fostered, how it impacts upon health and well-being, and how it can be managed to achieve maximum benefits with regard to health and well-being. It is the first in depth narrative investigation of resilience in people with SCI. Using both life story interviews and the process of timelining, participants' stories were collected. Following this they were then analysed using dialogical narrative analysis (Frank, 2010, 2012). This enabled participants' stories to be examined with regard to their effects on resilience and health and well-being. The analysis shows that firstly, due to the intangible nature of resilience, participants had trouble in articulating exactly what resilience meant to them. Instead, resilience was shown through participants' stories which could be grouped into four different narrative types: *loss*, *adaptation*, *posttraumatic growth (PTG)*, and *life-as-normal*. Together, these narrative types constructed resilience, and as such, resilience in people with SCI has four facets or 'faces', like a four-sided dice. The process of resilience in people with SCI worked by participants drawing upon the different narrative types at different times depending upon the demands being placed upon them. The loss narrative was drawn upon immediately following injury, and was concerned with the narration of the physical, psychological and social losses participants incurred following SCI. The loss narrative fostered resilience by enabling participants to talk about their losses, enabling participants to survive the hardest time of their lives. The second narrative type was the adaptation narrative. This narrative type focussed upon rehabilitation in both the spinal unit and in the community. This narrative type built resilience via progression through rehabilitation towards a quality of life comparable to pre-injury levels. The PTG narrative was concerned with the ways in which participants had developed following SCI and built resilience by shifting the focus onto the positives to come out of participants' experiences' of SCI. The life-as-normal narrative was used by two participants across their entire life story and enabled participants to continue with their lives with minimal disruption. It built resilience by placing disability in the background and therefore making it unimportant. This thesis then concludes with the empirical, theoretical, methodological and practical implications arising from this research. The potential for resilience to help improve the health and well-being of people with SCI is discussed, as well

as the ways in which resilience can have a maximum benefit on health and well-being of people with SCI.

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## **CHAPTER 1: Introduction**

### **What is this PhD about?**

Following spinal cord injury (SCI) the physical, psychological and social worlds in which people reside change drastically—from being highly accessible to highly restrictive (Smith, 2013a, 2013b; Smith & Sparkes, 2002, 2004, 2005, 2008; Sparkes & Smith, 2002, 2003, 2011). Nonetheless many people live healthy and happy lives following SCI (Quale and Shanke, 2010). Resilience is a concept used to explain what mitigates the impact of adversity and promotes well-being in children, youth, and adults from all over the world (Ungar, 2005; Wong & Wong, 2006). This PhD will take the concept of resilience and explore its role in the lives of men and women who have acquired a SCI. The approach it will take is a narrative one. This type of approach is especially suited to the study of both resilience and disability as stories embody the psychological and the social aspects of resilience in a social-relational approach to disability. A brief background to SCI, resilience and narrative shall now be provided.

### **Background**

#### **Spinal cord injury**

SCI is a devastating and traumatic injury (Gill, 1999; Krause, 1998) experienced by approximately 1,000 new people per year in the UK and Ireland (the majority of whom are young men) (Spinal Research, 2011). SCI affects the physical, psychological and social areas of a person's life (Belciug, 2001). Physical difficulties occur due to a change in the cord's normal motor, sensory, or autonomic function and include problems with mobility (most people use a manual or electric wheelchair in order to get around following SCI), a loss of sensation (including sexual), autonomic dysreflexia (a condition resulting in excessively high blood pressure), complications of the bowel and bladder (such as urinary tract infections), muscle spasms, pain, pressure sores, obesity (with 40% of people being overweight or obese following SCI) (Anson & Shepherd, 1996) and a difficulty in temperature regulation.

Following SCI people may also experience psychological difficulties. Research has shown that 20-25% of spinally injured people experience anxiety and 30-40% develop depression (Kennedy & Rogers, 2000). Furthermore, spinal cord injuries are usually incurred very suddenly and unexpectedly (e.g. falling off a horse or a tackle in a sport such as rugby

union). This is traumatic as people are not prepared for such a life changing event. Such sudden events can also be associated with frightening and disturbing memories, for example the memories from a car crash, or from war. This can give rise to post-traumatic stress disorder (PTSD) which is an issue in 10-40% of people following injury (Kennedy & Duff, 2001). Following SCI people are also at a higher risk of dependency, drug addiction and divorce. (Gill, 1999) as well as dissatisfaction with sex life (in 42% of males) (Phleps et al., 1983) and dissatisfaction with partner relationships (in 34% of people) (Franceschini et al., 2003). Spinal cord injured people may also experience sleep disturbances, for example awakening early, restless sleep, snoring, and difficulty in initiating and maintaining sleep (Bonekat et al., 1990). To add to these difficulties, spinally injured people may also experience poor attention span, limited initial learning ability, poor concentration ability, impaired memory function, and altered problem solving ability which may all serve to inhibit the initial rehabilitation process (Roth et al., 1989; Singh et al., 2012).

Social adjustment is also an area of difficulty following SCI. Singh et al., (2012) found that 34% of spinally injured people were a severe burden on the family, 32% had relationships with their partners that were lacking in friendliness and warmth, and only 34% of spinally injured people were able to continue to do their job or work at home following injury.

Resilience has been shown to be important during such physical, psychological and social difficulties, enabling physically ill individuals live and function better with their illness (Stewart & Yuen, 2011) as well as in the transitional process of learning to live with chronic illness (Kralik, van Loon & Visentin, 2006). Conditions where resilience has been shown to be important for health and well-being include rheumatoid arthritis (Smith & Zautra, 2008), diabetes (Kralik et al., 2006; Yi et al., 2008), chronic fatigue (Kralik et al., 2006), osteoarthritis (Wright, Zautra & Going, 2008), chronic pain (Sturgeon & Zautra, 2010), cancer (Brix et al., 2008) and depression (Wingo et al., 2010). Against this backdrop, the study of resilience may be an important influence on the health and well-being of people following SCI. The following section shall now provide an introduction to the concept of resilience.

## **Resilience**

Although we know that resilience is important following SCI (e.g. White, Driver & Warren 2008, 2010; deRoos-Cassini, Mancini, Rusch & Bonanno, 2010; Quale & Shanke, 2010;

Catalano, Chan, Wilson, Chiu, & Muller, 2011; Simpson & Jones, 2012), we know very little about what resilience is and how it is fostered, especially beyond the rehabilitation period. This research shall therefore examine resilience for spinally injured people who have left rehabilitation and now live in the community. Instead of focusing upon individualistic accounts of resilience (which have often been unhelpful in the lives of disabled people as they do not account the ways in which social oppression influences resilience and vice versa), this research shall consider not only the individual but also the family, community and culture in social ecological approach to resilience following SCI.

### **Narrative**

Narrative is especially suited to this research as narrative enables us to account for the psychological and social complexity of resilience for people with SCI. One reason for this is that by telling stories of disability, we can make available narrative resources that normalise the impaired body. This may go some way towards eradicating psycho-social disablism people with SCI are often subject to following SCI. Furthermore, by listening to disabled peoples stories of resilience, barriers in their environments can be identified and then eliminated (where possible). In this way resilience would become a product of not just personal resources, but also environmental resources.

Against this backdrop this PhD will explore the role of resilience in the lives of spinal cord injured people. This will include the exploration of how resilience is experienced and given meaning by people with SCI, as well how resilience is fostered, how it impacts upon health and well-being, and how it can be managed to achieve maximum benefits with regard to health and well-being. It is the first in-depth narrative investigation of resilience in people with SCI.

### **Overview of this thesis**

This thesis shall explore this resilience in people with SCI. This exploration is divided into nine chapters. **Chapter 1** (this chapter) has provided a brief outline of why it is important to study resilience in people with SCI as well as providing an outline of SCI and why it can be classed as an adversity. **Chapter 2** provides an overview of the current peer reviewed research which embeds the area of resilience for people with SCI from a narrative perspective. It will highlight the different ideas, concepts and theories in disability and resilience as well as tensions between contrasting perspectives. In doing so these gaps will be illuminated in our knowledge. **Chapter 3**



provides an outline of the qualitative methods and methodologies that were used in this research, and how they have been guided by my philosophical standpoint as a researcher. **Chapter 4** explores the meaning of resilience in people with SCI, highlighting the inherent difficulties in drawing a singular understanding of the concept. It will address the participants struggle to articulate resilience, and suggest that the participants actually showed resilience through their stories, rather than by telling what it meant to them. Four types of story will then be compared and contrasted to existing conceptualisations of resilience to highlight that resilience means different things at different points in time following SCI. **Chapter 5** introduces the concept of loss, before secondly looking at when stories of loss are told over time. This chapter then explores what stories of loss look like in people with SCI whilst considering the consequences of their telling in terms of resilience and subjective health and well-being. **Chapter 6** explores when stories of adaptation are told following SCI before moving on to unpack their general characteristics. This chapter will then explore why adaptation is so imperative in the process of resilience in terms of identity and independence, providing a justification for the promotion of stories of adaptation following SCI. **Chapter 7** looks at the different facets of the growth narrative in order to understand what stories of growth looked like, what enabled participants to tell stories of growth, and the consequences of telling such stories in terms of resilience and health and well-being. **Chapter 8** delves into the life-as-normal narrative, understanding what it looks like in people with SCI and what it does in terms of resilience and health and well-being in people with SCI. As well as this it shall touch upon why everybody cannot necessarily tell this type of story. **Chapter 9** concludes this thesis by summarising the empirical, theoretical, practical and methodological implications arising from this thesis. These include such things as the storied and relational nature of resilience, the oppression disabled people in this country often face, as well as how new and innovative techniques can be used in the research process.

## **CHAPTER 2: Literature Review**

### **Overview**

The purpose of this literature review is to provide an overview of the current peer reviewed research which embeds the area of resilience for people with SCI from a narrative perspective. It will highlight the different ideas, concepts and theories in disability and resilience as well as tensions between contrasting perspectives. In doing so gaps will be illuminated in our knowledge of resilience for people with SCI.

### **What is disability?**

Disability is complex to define. In the UK, the meaning of disability is fiercely contested between two opposing disciplines, medical sociology and disability studies. The crucial difference is that medical sociology views disability as a form of social deviance whereas disability studies regard disability as a form of social oppression. The social deviance lens posits that disability occurs when impairment violates social norms and in doing so, locates the cause of disability with the individual in a way that pathologises them. In contrast, the basis of social oppression is that people with impairment do not have the rights and resources taken for granted by the majority of the population, and are therefore excluded from participating to their fullest in society. This places the cause of disability with society in a social relational approach to disability.

Overlap does now exist between the two disciplines of medical sociology and disability studies and attempts have been made to build upon this common ground (Barnes & Mercer, 1996). Nevertheless, the divide has proved deep and irreconcilable (Thomas, 2004) as the assumptions informing the two approaches differ so drastically. These assumptions derive from the historical beginnings of each discipline, which shall now be discussed.

### **Medical sociology**

The study of disability began with the medical model and this influence still remains dominant within medical sociology, and also within sport psychology in terms of understanding disability. The medical model views impairment as a personal tragedy for the individual due to the limitations it places upon their ability to shape and organise the world around them as they wish (Swain et al., 2003). These limitations are perceived to violate the norms of a well-functioning

society. As such, disability is caused by impairment and entails some suffering and social disadvantage (Thomas, 2004). Medical sociology aims to rectify this suffering and social disadvantage by minimising or correcting the impairment to make the disabled person 'normal'. To do this, medical sociology has tended to focus on exploring the lived experience of pathology and society's responses to people who are 'abnormal'. This has some unequivocal problems as it reflects wider cultural assumptions around individuality, personal autonomy and self-determination in a society which places great value upon standing on your own two feet (Keith, 1994). This is problematic for people with impairment as they may never be able to fit this ideal of normalcy, or even want to. Indeed, Morris (1991) believes that the assumption that disabled people want to be 'normal' is one of the most oppressive experiences to which they are subjected, arguing for a rethink of the concept of 'normality' concept embedded in medical sociology. It was from this discontent the discipline of disability studies was born.

### **Disability studies and the social model**

Fuelled by the inequality and exclusion disabled people face within modern society a group of disabled activists created an alliance to promote their social interests and civil rights. They drew from Marxism and materialism to unsettle the common sense understanding of disability as arising from impairment, embedded within medical sociology. They argued that modern societies create disability as they are organised to suit the requirements of people without impairments and ignore the requirements of people with impairment (Oliver, 1996). As such, rather than changing the individual or chasing a medical cure, they believed that the focus should be towards social change, or even complete societal transformation (Corker & Shakespeare, 2002). In order to mobilise this social approach to disability and accumulate collective support, Finkelstein (1980) and Oliver (1990) created the social model of disability. This model is a practical resource which reinforces the argument that *all* restrictions in activity and therefore disability are caused by social barriers. It achieves this by creating a separation between disability and impairment, breaking the causal link between the two. Impairment remains, as in keeping with the medical model, a physical characteristic, but disability is reconstructed as a social and political process (Swain et al., 2003). This diverts political attention away from impairment and towards disability as being something imposed on top of impairments, something that is done to the person (Swain et al., 2003). The model has been transformative as it has enabled a vision of disabled people as free from the constraints of disability (oppression)

and provided a direction for commitment to social change, playing ‘a central role in promoting disabled peoples individual self-worth, collective identity and political organisation’ (Crow, 1996, p. 207). As well as this it has also become the principal point of reference in disability studies debates in Britain (Thomas, 2004). This is problematic, however as the model is not without its limitations.

### **Limitations of the social model**

The two overarching limitations of the social model are its simplicity and the divide between disability and impairment. These shall now be discussed in turn.

#### **The simplicity of the social model**

Designed for practical application, the social model of disability is only a simplification of the social relational approach to disability (Thomas, 2004). This means that the social model cannot be used as a theory or definition of the social relational approach as many of the approaches original tenets have been lost. Thus, the simplicity of the model, as well as being one of its greatest advantages is also its most fatal flaw (Shakespeare, 2006).

#### **The division of disability and impairment**

It is thought that any focus on impairment, and therefore the individual, their body, or psyche concedes ground on pathology, biological reductionism and medicine and would weaken the argument of the social model. Thus, in an attempt to deny the effects of impairment the social model of disability proposes a ‘separation between body and culture, impairment and disability’ (Hughes & Patterson, 1997, p. 326). This separation is problematic (Morris, 1991; Crow, 1992; French, 1993; Keith, 1994; Abberley, 1996; Crow, 1996; Pinter, 1996; Wendell, 1996; Garland Thomson, 1997; Hughes & Paterson, 1997; Shakespeare & Watson, 1997; Wendell, 1997) not only because it constitutes an outdated binary divide, but also because impairment is reduced to the biological, enabling it to be denied. By doing so this also rejects the body and lived experience which consequently essentialises people with disabilities. These limitations shall now be discussed.

#### **An outdated binary divide**

The modernist separation of ‘impairment’ and ‘disability’ is something seen as representative of outdated dualistic, binary, thought (Thomas, 2004). Indeed Shakespeare and Watson (2001)

write: 'Impairment and disability are not dichotomous, but describe different places on a continuum, or different aspects of a single experience. It is difficult to determine where impairment ends and disability starts' (p. 22).

### **Impairment is reduced to the biological**

The separation of impairment and disability is related to a problematic reduction of impairment to the biological (Shakespeare & Watson, 2001; Hughes & Paterson, 1997; Hughes, 2002). As well as inadvertently medicalising impairment, this separation does not recognise the ways in which impairment is socially constructed. For example it does not take into account the idea that 'the words we use and the discourses we deploy to represent impairment are socially and culturally determined' (Shakespeare & Watson, 2001, p. 18).

### **The denial of impairment**

The division of disability and impairment suggests that impairment does not affect disability. According to Shakespeare and Watson (2001) and feminists such as Thomas (2004), Morris (1991), French (1993) and Crow (1996), saying that all restrictions and thus disability are caused by social barriers is too simplistic and just not the case, impairments *do* have real effects on disability. 'People are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial' (Shakespeare & Watson, 2001, p. 17).

### **The denial of the body**

By denying impairment, the social model does not take into account the body. Oliver (1996b, pp. 41-42) exemplifies this point when he wrote that 'disability is wholly and exclusively social... disablement has nothing to do with the body'. Here physicality is cast out into the shadows (Hughes & Patterson, 1997) creating a disembodied research agenda. Disembodied research within sociology or psychology is problematic due to the fact that people live through their bodies and as such the body matters. This is especially so in the study of many disabilities, such as SCI, due to their physical nature. People *are* restricted by their impaired bodies. Furthermore, by not accounting for the lived body, the embodied experience of prejudice, oppression and discrimination (or in other words, the experience of the psycho-emotional dimensions of disability) are not taken into consideration (Hughes & Patterson, 1997; Reeve, 2002). Disability studies as a discipline is only just beginning to account for the body through scholars such as

Abberley (1987), Morris (1991), and French (1993). To progress this area further the discipline could utilise ideas concerning the body from medical sociology (e.g. Bury, 2000; Williams, 1999), as well as by taking into account the individuals lived experience.

### **The denial of lived experience**

The social model focuses on the ‘public’ experiences of oppression, such as inaccessible environments, rather than more ‘personal’ experiences of oppression such as the effects of impairment (Thomas, 1999). Indeed, Finkelstein (2001b) objects to the washing of this personal dirty linen in public, except if it is supporting the broader struggle for social change. This is because the lived experience of impairment has often been seen as a personal tragedy, thought to weaken the case for collective social transformation. This has meant that disability studies scholars have kept their distance and the lived experience of impairment has largely remained private. Feminists argue that this should not however be the case and that the personal is political (e.g. Morris, 1992, 1993). They suggest that macro level research approaches such as Marxism, materialism and post-structuralism silence individual voices, inadvertently incorporating a tacit but powerful rendering of their subjective experience as illegitimate (Watermeyer & Swartz, 2008). These individual voices are often the ones of less powerful groups in society. Instead, more powerful others speak for these groups and define their needs. Therefore it is crucial that individual experience is listened to so that both the political and emotional consequences of disablism are understood (Watermeyer & Swartz, 2008). The individual lived experience of impairment cannot be ignored and it is the denial of individual experience that now limits disability studies (French & Swain, 2006).

### **Essentialism**

Finally, by neglecting impairment all people with impairment are treated as a homogenous group. Although this can help create a strong disability identity and a collective stance in the case of campaigning for disability rights, treating every individual with impairment as the same essentialises people with disabilities, denying their difference and inadequately accounting for the milieu of different types of disability and personal experiences of impairment.

## **Overcoming the limitations of the social model**

In order to overcome these limitations, different ways of taking into account impairment, the body and lived experience have been proposed. Post-structuralists have re-theorised impairment in attempt to challenge the dichotomy between the body and politics and create a non-dualistic theoretical perspective (Hughes & Paterson, 1997). This means that impairment would be seen as a social construct, allowing it to be explored without reducing it to medicine. Another way to deconstruct these binary divides is to view impairment and disability as different aspects of experience along a continuum (Shakespeare & Watson, 2001). Impairment could be explored without medicalising it as everyone would be seen as impaired to different degrees, collapsing the normal/ abnormal dualism. Feminists suggest that the model can take into account impairment, through the concept of impairment effects (Thomas, 1999).

## **Impairment effects**

Impairment effects do not constitute disability but are the restrictions of activity which result from living with impairment. The experience of living with impairment is also culturally situated and socially mediated. Thus, impairment is considered as both biological and social, or biosocial (Thomas, 1999). Instead of weakening the political power of the social model, acknowledging impairment is politically unifying because it enables a full range of disability experiences to be recognised and this inclusivity will better represent all disabled people in society (Thomas, 2001). In doing so this also disrupts the essentialised nature of the social model by extending it to include discussions concerning the very real, biological nature of the individuals' body and psychological experience, known as psycho-emotional disablism (Thomas, 1999).

## **Psycho-emotional dimensions of disability**

Psycho-emotional dimensions of disability account for the psychological experience of the disabled person that affects their emotional well-being. This includes their experiences of exclusion, discrimination and prejudice. Defined by Thomas (2007), 'Psycho-emotional disablism involves the 'intended or unintended 'hurtful' words or social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments. It involves the creation, placement and use of denigrating images of 'people with impairments' in public spaces by the non-disabled' (p. 72). These perceptions are relayed to the disabled person through their relationships with others, potentially harming the

individual. Furthermore these attitudes may be internalised, making a person feel worthless and unattractive. It is argued by Shakespeare et al., (1996) that it is these psycho-emotional barriers have the most disabling consequences on people's lives. This is because 'dealing with anger, self-loathing, and daily experiences of rejection and humiliation are among the hardest aspects of being a disabled person' (pp. 42-43). They affect who a disabled person can be, not just what they can do. Disabled people may employ strategies in order to counteract disablism. 'Emotional work' may be used either to hide their own emotions in line with rules in society, or to manage the emotions of others (Lupton, 1998). This 'emotional dissonance' is a recognised aspect of emotional labour which can lead to emotional exhaustion (Ashforth & Tomiuk, 2000, p. 19). This dissonance can have an adverse effect on the physical and emotional health of a disabled person. The experience of psycho-emotional disablism is not inevitable because disabled people can resist narratives in society that inflict psycho-emotional disablism, and may also transform themselves by locking into counter narratives that see disability as a positive identity (Reeve, 2002). Research needs to take into account the emotional and physical effects of psycho-emotional disablism and resistance to psycho emotional disablism (Reeve, 2006). In doing so this also restores links between disability studies and psychology, accounting for both the psychological and the social in a relational approach to disability.

### **Social relational disability**

A social relational approach to disability is established by recognising impairment, its physical restrictions, and its psychological dimensions. This approach encompasses the oppression at both micro and macro level, in the relationships between disabled and able bodied people (Thomas, 2004). From this perspective 'disability is 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 well-being' (Thomas, 1999, p. 3). Thomas believes that this understanding of disability provides a firm foundation for an enriched view of disability, suggesting that it is in this direction that disability studies should be moving.

### **Health and Well-being following spinal cord injury**

SCI is an injury to the spinal cord resulting in a change in the cord's normal motor, sensory, or autonomic function. The level of injury is one of the main categorical measures of the physical severity of SCI. Paraplegics acquire a break of the back (Thoracic (T) vertebrae 1-12, Lumbar



(L) vertebrae 1-5 or Sacral (S) vertebrae 1-5) and tetraplegics (also known as quadriplegics) acquire a break of the neck (Cervical (C) vertebrae 1-7). Due to a higher level of injury those with tetraplegia have a lower level of physical function than those with paraplegia. This is also true within groups for example those with a higher level of tetraplegia for example C1 (the highest level of SCI) will have less function than someone with a C7 level of injury. Differences can also occur between those with the same level of injury. For example a person may have a complete lesion of the spinal cord (the spinal cord is no longer intact) or an incomplete lesion of the spinal cord (the spinal cord remains partially intact). A person with a complete injury will have no sensation or movement below the level of injury where as a person with an incomplete injury may have some sensation and movement, and may even be able to walk with a walking aid. Furthermore, two people with the same level of injury could have different levels of function due to individual and environmental factors. For example, the process of rehabilitation may have a great influence on the function of an individual following SCI. At the current moment in time there is no medical 'cure' for SCI and therefore those who become spinal cord injured must live with adversity for the rest of their lives.

## **Health**

In 1948 the World Health Organisation (WHO) defined health as 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.' At the time this definition was revolutionary as it accounted for health in a more positive and all-encompassing way (rather than a negative and narrow way) and it included the physical, mental and social domains of health (Huber et al., 2011). However, this definition has been criticised for being idealistic and utopian as 99% of the world's population cannot meet this standard and therefore must be in need of care and attention (Garner, 1979). Another criticism of this definition has been that it categorises the growing number of people living with chronic diseases and disabilities (including those with SCI) as ill (Huber et al., 2011). This is problematic for Callahan (1973) who argues that 'one can be healthy without being in a state of 'complete physical, mental, and social well-being' (p. 87). Taking this into consideration, it is more helpful to define health as 'the ability to adapt and self-manage' (Huber et al., 2011, p.343). This definition accounts for health across physical, psychological and social domains.

Health can therefore be understood to mean different things to disabled people than it does to non-disabled people. People with disabilities see themselves as healthy as long as they are not ill. This means that for a disabled person unhealthiness equals illness. As such, if physically disabled people are not ill, they are healthy in spite of their impairment (Nazli, 2012). Avoiding illness can be challenging for disabled people however due to the fact that people with SCI have to contend with sensory and motor deficit which can compromise their ability to organise their lives as they wish following injury. For example, a person with SCI may experience difficulties with feeling when parts of their bodies come into contact with boiling objects, which may result in being burned by an oven or a kettle. These are known as secondary complications. There are many secondary complications that affect a person's health (see p. 12), including poor mental health (otherwise known as well-being).

### **Well-being**

Well-being is difficult to define and is understood in different ways across the psychology literature (Keyes, Shmotkin & Ryff, 2002; Snyder & Lopez, 2007). These different ways of understanding can be split into two main traditions, subjective well-being (SWB) and psychological well-being (PWB) (Keyes et al., 2002). SWB (or the hedonic approach) can be understood in terms of life satisfaction (a person's perceived distance from their aspirations), combined with high positive affect and low negative affect (or happiness) (Campbell, Converse & Rodgers, 1976; Keyes et al., 2002; Hefferon & Boniwell, 2011). PWB (or the eudemonic approach) is concerned with meaning, human development and existential challenges (Ryan & Deci, 2001; Keyes et al., 2002). Six key dimensions constitute PWB, these are: self-acceptance, positive relatedness, autonomy, personal growth, life purpose and environmental mastery (Ryff & Keyes, 1995).

Although divergent, these two approaches can also be complementary (Ryan & Deci, 2001) as both perspectives 'embody humanistic values that elevate the human capacity to examine what makes life good' (Keyes et al., 2002, p. 1017). Furthermore, 'without happiness and life satisfaction it is unlikely that psychological growth and development will occur, and when meaningful life experiences are lacking, happiness and life satisfaction may decrease' (Williams, 2015, p. 15). As such, in order to fully explore well-being, both SWB and PWB need to be taken into consideration (Lundqvist, 2011; Williams, 2015). SCI presents individuals with a

traumatic challenge to their well-being (Pollard & Kennedy, 2007). Indeed, the ‘psychological impact of paralysis is more devastating than the inability to walk’ (De-Santo-Madeya (2006, p.276). In terms of SWB spinally injured people may experience mental health conditions such as anxiety or depression (see p. 12-13), and in the case of PWB people may experience a loss of purpose in their life (Geyh et al., 2012). Both SWB and PWB therefore need to be taken into account when exploring well-being following SCI.

### **Summary of the disability literature**

Viewing disability through the social model marked a crucial change in how disability is conceptualised. Instead of seeing the social disadvantage disabled people face as an inevitable consequence of impairment, the social model suggests that society disables people with impairments as it does not account for their needs. The social model, combined with the inclusion of impairment effects and the psycho-emotional consequences of disablism, re-establishes a social relational approach to disability. This takes into account the oppression disabled people face in society as well as the real effects of impairment, the body and lived experience and as such allows for the exploration of the psychological and social aspects of disability. The next section shall now explore resilience.

### **Resilience**

#### **What is resilience?**

It is very difficult to define resilience in a universal, singular way. This is due to the ambiguous use of central terminology across the resilience literature, as well a long standing debate between scholars over how resilience should be conceptualised and operationalised (Luthar, Cicchetti, & Becker, 2000; Fletcher & Sarkar, 2013). It is for this reason that instead of offering a definition of resilience this review shall outline the two common threads which hold the literature on resilience together. These threads are adversity and positive adaptation (Luthar, 2006; Luthar & Cicchetti, 2000; Luthar, Cicchetti, & Becker, 2000). The body of research which embeds these threads can be divided into four waves of inquiry, closely aligned with resilience’s theoretical development. These waves of inquiry shall now be discussed.

### **The first wave of inquiry**

Resilience research originally began with the study of at risk children in an attempt to understand the causes of psychopathology. Rather than showing symptoms of psychopathology, however, investigators found that many children did very well, thriving in the face of adversity. In an attempt to understand this phenomenon, studies sought to identify the characteristic traits which made these children resilient (Garmezy, 1974; Garmezy & Rutter, 1983; Murphy & Moriarty, 1976; Rutter, 1979; Werner & Smith, 1982). As the study of resilience developed, research went beyond identifying psychological and dispositional attributes associated with resilience towards recognising resilience as a state dependent upon a number of environmental variables such as family support, family cohesion and external support systems (Garmezy, 1991; Rutter, 1990; Werner & Smith, 1992). This prompted a debate, still underway today, concerning whether resilience should be conceptualised as a *trait* or a *state*. Most scholars have now come to agree that resilience is a state due to the premise that relations between an individual and their environment change with the passage of time (Lerner, Dowling, & Anderson, 2003; Ungar, 2010). This gave rise to the second wave of inquiry concerned with *how* resilience evolves over time.

### **The second wave of inquiry**

The second wave of inquiry aims to explore the processes and mechanisms underpinning resilience. So far over a dozen theories have been proposed which claim to explain the process of resilience (see Fletcher & Sarkar, 2013). Many of these theories however have limited use for the study of people with SCI however as they do not take into account the ways in which individuals are oppressed by their environment. For example, although the metatheory of resilience and resiliency (Richardson, 2002; Richardson, Neiger, Jensen, & Kumpfer, 1990) is commonly cited across the literature (e.g. Agaibi & Wilson, 2005; Campbell-Sills et al., 2006; Connor & Davidson, 2003; Denz-Penhey & Murdoch, 2008; Galli & Vealey, 2008; Gu & Day, 2007; Sinclair & Wallston, 2004; White, Driver, & Warren, 2008), it fails to account for the influence of family, community and culture on resilience, instead seeing resilience as ‘a self-righting force *within* everyone that drives him/her to pursue self actualisation, altruism, wisdom, and harmony with a spiritual source of strength’ (Richardson & Waite, 2001, p. 65, italics added). Sturgeon and Zautra (2010) offer an alternate theory of resilience.

Sturgeon and Zautra (2010) break down the process of resilience by dividing the outcome into three differential resilience responses: *recovery*, *sustainability* and *growth*. *Recovery* 'refers to the extent to which the person regains equilibrium, following upsetting events'. *Sustainability* refers to 'the perseverance of desirable actions, goal pursuits, and social engagements that are sources of positive emotion and self-esteem' and *growth*, refers to 'the realization of greater understanding of one's capacities, and new learning that arises as a consequence of the stressful experience and outcomes of one's coping efforts' (p. 106). This theory addresses the main limitation of Richardson's (2002, 1990) theory as it enables resilience to be studied from multiple levels of analysis (see Reich, Zautra & Hall, 2010), thereby accounting for the family, community and culture.

### **The third wave of inquiry**

There are two conflicting schools of thought pertaining to what the third wave of inquiry entails. For Richardson (2002), and Fletcher and Sarkar (2013) the third wave of resilience research concerns the innate need for resilience. Richardson explains: 'A succinct statement of resilience theory is that there is a force within everyone that drives them to seek self-actualization, altruism, wisdom, and harmony with a spiritual source of strength. This force is resilience, and it has a variety of names depending upon the discipline' (p. 313). For Masten (2010), however, the third wave tests processes of resilience through interventions that are designed to promote well-being in at risk populations. Interventions have included stress management and prevention (Steinhardt, & Dolbier, 2008), cognitive behavioural psychology (Padesky, & Mooney, 2012), resilience skills training (Reivich, Seligman, & McBride, 2011) and psychotherapeutic methods (Fava, & Tomba, 2009). Although the success of interventions has so far been limited, the hope is to develop interventions that successfully improve resilience and health and well-being in those who are most at risk.

### **The fourth wave of inquiry**

The fourth wave of inquiry, now underway (Masten, 2007; Wright & Masten, 2005), seeks to assimilate and advance knowledge from the first three waves through a systems approach. It posits that changes in behaviour are likely to result from multiple causes (multicausality), and as such, common endpoints in final pathways can result from diverse beginnings (equifinality), and vice versa (multifinality) (Masten, 2007). This enables us to explore the dynamics of adaptation

and change across multiple disciplines and levels of influence. The systems approach informs the social ecological model of resilience.

### **The social ecological approach**

The social-ecological approach is based upon the premise that resilience is the product of the individual and their environment, taking into account family, community and culture:

In the context of exposure to significant adversity, whether psychological, environmental or both, resilience is both the capacity of individuals to navigate their way to health sustaining resources, including opportunities to experience feelings of wellbeing, and a condition of the individuals family, community and culture to provide these health resources and experiences in culturally meaningful ways' (Ungar, 2008, p. 225).

This definition of resilience is useful as it takes into account unique, heterogeneous understandings of resilience across cultures and contexts as well as global, homogenous understandings of resilience across cultures and contexts. Homogeneity can be represented by seven tensions. These are identity, relationships, access to material resources, social cohesion, power and control, social justice, and cultural adherence (Ungar et al., 2007). Although these tensions are consistent across the globe, they are resolved by different cultures in heterogeneous ways. When viewed across cultures and contexts, resilience as an outcome is therefore indeterminate (Ungar, 2010). For example, resilience resulting from a natural disaster would not necessarily be similar to the resilience following cancer due to the corporeal nature of the illness related trauma and the process of physical reconnection with the body (Hefferon, Grealy & Mutrie, 2009). Thus, the context and population in which resilience is embedded is therefore important, and needs to be specified. Studied contexts have included bereavement (e.g. Bonanno et al., 2002), terrorism (e.g. Hobfoll et al, 2009), abuse (e.g. Singh, Hays, Chung, & Watson, 2010), and illness (e.g. Kralik, Visentin & Van Loon, 2006). Understudied, however, is the context of disability.

### **Resilience and disability**

There is an absence of notions of resilience in the lives of disabled people (Olkin, 1999; Prilietenksy, 2009). Although this is in part due to a lack of research, is also because disabled people are often excluded from the category of *resilience*, and placed in the category of

*vulnerable* (Runswick-Cole & Goodley, 2013). This highlights a number of problems in the way resilience has been understood in relation to disabled people.

Firstly, in relation to disability, resilience has too often been viewed as ‘the positive pole of individual difference in people’s response to stress and adversity’ (Rutter, 1987, cited in Young, Green, & Rogers, 2008, p. 41). This has a number of consequences. Firstly, disabled people are blamed for their perceived lack of resilience to overcome ‘their lot in life’ (Ungar, 2005, p. 91), and secondly, disabled people are accused of using disability as an excuse for not showing resilience (Runswick-Cole & Goodley, 2013). This contributes to the oppression of disabled people in society. To overcome this scholars have either adopted a social-ecological approach (Cárdenas & López, 2010; Porcelli, Ungar, Liebenberg & Trépanier, 2014), or a social constructionist approach (Runswick-Cole & Goodley, 2013) to the study of resilience in the disabled.

Secondly, traditional approaches assume that to show resilience a disabled person must become a supercrip (Runswick-Cole & Goodley, 2013). ‘Supercrips are those individuals whose inspirational stories of courage, dedication, and hard work prove that it can be done, that one can defy the odds and accomplish the impossible’ (Berger, 2008, p. 648). Stories of the supercrip are therefore thought to be problematic for disabled people as they encourage unrealistic expectations about what people with disabilities can, and should be able to achieve. Again, this encourages society to blame the disabled person for not showing resilience.

Thirdly, little is known about what it means to show resilience outside of *ableist cultures* (cultures which affirm normative modes of being and diminish lives that are judged to differ from the norm) (Ungar, 2004; Runswick-Cole & Goodley 2013, p. 71). As such, disabled people are often evaluated against able-bodied understandings of resilience. These understandings of resilience usually involve a person overcoming disability in order to live their life like a non-disabled person might (Runswick-Cole & Goodley, 2013). This is problematic for disabled people as they may not want to live their life like a non-disabled person. Furthermore, any non-normative ways in which they may show resilience could be missed, or even more troublingly, judged as signs of vulnerability. Before making judgements based upon resilience, future studies need to understand what resilience is in people with disability.

Finally, only a single study (Porcelli, Ungar, Liebenberg & Trépanier, 2014) has taken into account the effects of impairment in relation to resilience. This study is significant as it suggests that a) impairment effects are important in the study of resilience (and vice versa), and that b) impairment effects can be studied from a standpoint that isn't oppressive, overcoming the impairment disability dichotomy evidenced in the social model. This paves the way for the use of a social relational approach to the study of disability meaning that more research (including research on resilience) can overcome the impairment disability dichotomy in order to take into account the multiple aspects of disabled people's experience (physical, psychological and social) (Anastasiou and Kauffman, 2013).

### **Resilience in people with SCI**

Research which has studied resilience in the lives of disabled people has mainly focused upon a) those with learning disabilities (Morrison & Cosden, 1997; Miller, 1996, 2002), b) those with psychiatric disabilities (Deegan, 2005), c) children with disabilities (Alriksson-Schmidt, Wallander & Biasini, 2007; Armstrong, Birnie-Lefcovitch & Ungar, 2005), d) adults who became physically disabled early on in life (before the age of 7) (King, Brown & Smith, 2003), and in particular e) the families of children with disabilities (Patterson, 1991; Horton, Wallander, 2001; Heiman, 2002; Gardner & Harmon, 2002; Rolland & Walsh, 2006; Bayat, 2007; Lloyd & Hastings, 2009; Gerstein, Crnic, Blacher & Baker, 2009). We know very little about resilience in adults who acquire a physical disability.

Dunn, Uswatte and Elliott (2009) provide us with some insight into resilience in adults with an acquired physical disability. They firstly suggest that positive emotions are important when it comes to resilience as they help psychological and physiological functioning return to baseline levels (see Fredrickson, 2006; Fredrickson, Tugade, Waugh, & Larkin, 2003; Tugade and Fredrickson, 2004). Secondly, they suggest that resilience should not be required, only encouraged. This is because there is no single way to respond to adversity.

Six studies have explored the concept of resilience specifically in relation to traumatic SCI. In 2008 White, Driver and Warren were the first scholars to underline the importance of resilience in the spinal cord injured when they identified its importance following injury. They expanded on this in 2010 by quantitatively examining the change in resilience during the rehabilitation period. This was also the first study to specifically study SCI. Although results



showed no significant change in resilience during the rehabilitation period, there was significant change for indicators of adjustment. It is possible that resilience is hidden when using questionnaire techniques as they impose outsider's definitions of resilience upon this unique population.

A study by deRoos-Cassini, Mancini, Rusch and Bonanno (2010) longitudinally examined psychological adjustment after severe physical injury by identifying four trajectories explaining adjustment to SCI. These were *resilience*, *recovery*, *delayed distress* and *chronic distress*. Although *resilience* was the most common trajectory, this finding must be taken with caution as *resilience* was only inferred from the absence of psychopathology and not from positive development. In 2010, Quale and Shanke built upon these findings through the use of questionnaires and semi-structured interviews. They also found that resilience was the most common trajectory out of the four, and that it could be predicted by trait positive affect and trait negative affect. The different trajectories were also differentiated by optimism, social support and pain. They suggested that an optimal level of coping and self-efficacy led to resilience, and that higher levels of education appeared to be protective.

Catalano, Chan, Wilson, Chiu, and Muller (2011) studied resilience in people with SCI by applying the Framework of Resilience Model (FRM; Kumpfer, 1999) to their own model of resilience. They tested their model using structural equation modelling and found that social support and problem-focused coping had a direct effect on resilience. Resilience, in turn, buffered depressive symptoms, operating as a mediator between perceived stress and depressive symptoms.

The most recent study concerning resilience and SCI was conducted by Simpson and Jones (2012) when they investigated the relationship between resilience and a) affective state, b) caregiver burden, and c) caregiving strategies among family members of people with traumatic brain injury or SCI. They found that family members' self-rated resilience correlated positively with positive affect, and negatively with both negative affect and caregiver burden. Although these findings support the construct of resilience, it is difficult to relate these findings to resilience in the spinal cord injured as the study was concerned with their family members and not the individuals themselves.

## **Resilience and the impact of sport**

Sport and physical activity have been associated with improved health and well-being for people both with and without disability. Furthermore, exercise adherence has consistently been linked to resilience in people with physical illness or injury (Stewart & Yuen, 2011). The majority of spinal injured people have led very active lives prior to their injury and many are even injured through playing sport. The physical limitation that occurs with injury may hinder the type of and amount of activity that an individual can do. This can trigger feelings of frustration, worthlessness and helplessness (Mukai & Costa, 2005). In addition people with SCI may be faced with poor access to sports facilities (Tasiemski, Kennedy, Gardner & Taylor, 2004) which is one of the main reasons why following injury, participation in sport and physical activity decreases significantly with nearly 40% of people stopping physical activity altogether (Tasiemski, Kennedy & Gardner, 2006). Cessation of physical activity will result in a loss of the benefits that being physically active can bring. Furthermore, it may result in the loss of athletic identity as well as sense of belonging to a wider sporting community, and the networks of support that accompany this.

However, instead of dropping out from sport and physical activity, many people take up wheelchair sport once they have returned to living in the community. Overall 47% participate in physical activities (20% in sport and 27% in recreation) (Tasiemski, Bergström, Savic & Gardner, 2000). Of these people, 4% had not previously been physically active before the injury. Tasiemski et al (2004) found that those involved in physical recreation or sport after injury had a significantly higher rating of life satisfaction than those who weren't participating suggesting that sport and physical activity may be related to a person's resilience. This relationship needs further exploration.

## **Summary**

In summary resilience has traditionally been understood as a psychological phenomenon consistent across cultures and contexts. This has led researchers to impose emic understandings of resilience upon the disabled population which not only obscures what resilience is in this population, but more worryingly obscures the ways in which society oppresses people with disabilities. This has led people with disabilities to be blamed for not showing resilience to disability.

Secondly, although community integration has been described as the ultimate goal in the rehabilitation of individuals following an injury or disability (Wood-Dauphinee & Williams, 1987; Donnelly & Eng, 2005), we know very little about resilience in people with SCI beyond the context of rehabilitation. As such, little is known about how adjustment during rehabilitation relates to the reality of living with SCI over the long term (Carpenter, 1994). This is problematic as return to the community is likely to be an especially difficult period for people with SCI as they leave an environment which is fully adapted and supportive, to an environment which may be un-adapted and un-supportive.

This PhD shall address these two gaps in the literature by firstly accounting for the influence of family, community and culture on resilience. This will provide an understanding of what resilience is in people with SCI, contextualising resilience. Secondly, this PhD shall explore the process of resilience in people with SCI from the moment of injury, through rehabilitation and beyond to life in the community (i.e. how is resilience built?). Against this backdrop the aims of the research and the central research questions are as follows.

### **Aims of the research**

1. Explore resilience, health, and well-being among spinal cord injured adults living in the community through in-depth life story interviews and timelining.
2. Advance theoretical understandings within the fields of health sciences and disability concerning resilience, health, and well-being
3. Advance methodological understandings within the fields of health sciences and disability through the employment of a combination of in-depth life story interviews and timelining.
4. Assist health practitioners and policy makers in promoting resilience and improving the health and well-being of disabled people and their families.

### **Central research questions**

1. How is resilience experienced and given meaning by spinal injured adults? (Aims 1 & 2)
2. What and where are the sources of resiliency for spinal injured adults? (Aims 1, 2 & 4)

3. What facilitates or impedes resilience in the face of disability, ill health and well-being? (Aims 1, 2 & 4)
4. How does resilience influence health and well-being and how can these influences be managed to achieve maximum benefits? (Aims 1, 2 & 4)

## **CHAPTER 3: Methodology and methods**

### **Introduction**

Throughout the research process I have had to make many decisions regarding the approach I have taken towards answering the research questions. As such, the nature of the knowledge produced in this thesis is shaped by my philosophical standpoint as a researcher. In order to provide transparency this chapter shall firstly summarise my paradigmatic assumptions, secondly, provide a brief introduction to qualitative research and narrative, and thirdly, outline the methods of data collection and analysis I have used during the research process.

### **Paradigmatic assumptions**

All researchers approach the world through a particular paradigmatic lens. Paradigms are a way of breaking down the complexity of the real world, encompassing our most basic, fundamental beliefs about it (Sparkes, 1994). These beliefs comprise of our ontology (the nature of reality), our epistemology (the relationship between the knower and the known), and our methodological standpoint. These beliefs cannot be proved or disproved as they are so basic they have to be accepted simply on faith (Guba & Lincoln, 1994). In social science there are four broad paradigms of a) positivism, b) post-positivism, c) interpretivism, and d) critical realism.

- a) Positivism is the oldest and often deep rooted paradigm in science. Ontologically it assumes that there is a singular reality which we can objectively access in order to know the truth about the world.
- b) Post-positivists also believe in a singular reality and objective truth, however, unlike positivists they believe that epistemologically our methods of getting at the truth are flawed. As such, they believe that our knowledge of the truth is only true until it can be disproved. Post-positivists therefore concentrate on falsifying hypotheses rather than trying to verify them.
- c) Interpretivism is based on the ontological belief that there are multiple realities in that each and every one of us constructs our own version of reality when we view the world. Therefore, epistemologically, knowledge is socially constructed.
- d) Critical realism falls in between positivism and interpretivism. Although critical realists believe in a singular reality they acknowledge that we cannot directly access this reality

as we cannot escape our own subjectivities. Critical realists therefore concentrate on trying to get as close as possible to the truth.

At this point in time my beliefs about the world sit with those of an interpretivist. I believe in a relativist ontology in that there are multiple realities, and a constructionist epistemology in that knowledge is socially constructed.

### **Social construction**

Social constructionism posits that each individual constructs their own version of how they see the world and this is influenced by society around them. Each individual cannot therefore escape their own subjectivity and as such all knowledge is situated and relative to a particular individual, culture and time. Within constructionist research both the knower and the known have to be taken into account and thus the researcher has to provide transparency by stating their standpoints and assumptions throughout the research process. As I believe that each individual constructs their own reality I am drawn towards qualitative research, exploring how individuals construct and experience their own version of the world and create meaning in their lives.

### **Qualitative research**

#### **What is qualitative research?**

Qualitative research is difficult to define as it can mean different things to different people. Furthermore, it is surrounded by a complex, interconnected family of terms, concepts and assumptions (Denzin & Lincoln, 2011). Denzin and Lincoln (2011) present one understanding of qualitative research:

Qualitative research is a situated activity that locates the observer in the world. Qualitative research consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense or interpret phenomena in terms of the meaning people bring to them. (p. 3)

Qualitative research is especially suited to the study of resilience in people with SCI as it explores meaning, contextualises research, represents minority voices, and accounts for subjectivity, lived experience and the body. These points shall now be discussed.

### **The exploration of meaning**

‘Meaning is basic to being human and being human entails actively construing meaning. Thus, in order to understand ourselves and others we need to explore the meanings that make up our worlds’ (Smith & Sparkes, 2008, p. 18). Qualitative research enables us to do just this, helping to illuminate not only what is happening in our lives, but also how and why things are happening in the way that they do. This is imperative in the study of resilience in people with SCI as it gives us an understanding of what resilience can mean as well as how resilience can be created in this population. Meaning is also important in the study of disability as it can give us an understanding of the different meanings people ascribe to SCI as well as what these meanings do in terms of resilience and health and well-being.

### **Contextualising resilience and representing minority voices**

Ungar (2004, 2005, 2006) has suggested that a major limitation of resilience research is that it doesn’t fully account for the community and cultural factors that contextualise how different populations define resilience and manifest it in their day to day lives. Instead research has tended to infer resilience using arbitrary variables (Ungar, 2003) that are often biased towards certain understandings of resilience (i.e. what resilience is taken to mean in white, western, able bodied populations). Being ideographic by nature, qualitative research is concerned with the exploration and subsequent representation of individual lives in great depth and complexity. This helps to overcome hegemonic standards of resilience by eliciting and adding power to minority ‘voices’ (Ungar, 2003). As such, marginalised groups in society (such as the disabled) can create their own unique definitions of resilience (Ungar, 2003), working to illuminate and validate examples of hidden resilience which are culturally and contextually specific (Ungar, 2006).

### **Accounting for subjectivity**

The interpretive nature of qualitative research recognises that research is affected by the subjectivity of both the researcher and the participants. The researcher is encouraged to reflect upon how the participants’ subjectivities have affected the way that they respond to the research

(and the researcher), and the how the researcher's subjectivities have influenced how they have interpreted the world of the participant and how they have represented the participant. This is important as researchers studying resilience need to consider their biased standpoints (Ungar, 2003). Reflecting on subjectivities is also useful as it brings moral and ethical considerations to the forefront of research.

### **Lived experience and the body**

French and Swain (2006) suggest that it is the denial of individual experience that now limits disability studies. This is because by denying individual experience disability studies fails to account for the psycho-emotional dimensions of disability, as well as the effects of impairment. As well as creating a disembodied sociology, this also does not account for the ways in which impairment and disabled bodies influence people's resilience following disability. Qualitative research helps to overcome these limitations as it is suited to the exploration of individual lived experience, the body, impairment and the psycho-emotional dimensions of disability (Sparkes & Smith, 2002; Smith & Sparkes, 2008).

This section has outlined the reasons why qualitative research is suited to the study of resilience in people with SCI. The next section shall build upon this by suggesting why the exploration of people's stories through narrative inquiry in particular is an appropriate way of qualitatively exploring the topic of interest.

### **Narrative**

Narrative is an ontological and epistemological condition of life (Somers, 1994; Smith & Sparkes, 2006) which posits that we are storytelling animals (MacIntyre, 1981), living in a world shaped by stories (Bruner, 1990). Our lives therefore depend upon the stories that we construct in order to know, understand and make sense of our social world (Somers, 1994) across time (Crossley, 2003). Our knowledge of the social world is therefore subjective, constituting a partial, narrative truth that can never be separated from the person by whom it is known.

### **What is a narrative?**

Narrative means different things to different people. As such, when Smith and Sparkes (2009) define narrative as 'a complex genre that routinely contains a point and characters along with a plot connecting events that unfold sequentially over time and in space to provide an overarching



explanation or consequence' (p. 2, emphasis in original), they stress that this definition should be seen as an offer of what narrative can be, rather than a fixed or final answer to what narrative is. Other ways of understanding a narrative are also useful, especially when deciphering a narrative from a story. One such understanding views a narrative as a template people use to tell their stories. As such, not all stories can be called a narrative as unlike stories, narratives have certain structures which hold them together.

### **What is a story?**

Stories do not merely depict things, they also do things. Acting as companions they work with people, for people and on people, affecting what people are able to see as real, as possible, and as worth doing or best avoided (Frank, 2010). The stories people live by therefore shape who a person is and who they can become. As well as this, stories also contain. This is useful for resilience following SCI as it means that stories have the capacity to put things that negate resilience at a distance, or bring things that foster resilience to the forefront. They can therefore help people lead better lives or heal parts of ourselves that have been broken (Frank, 2010). In order to understand resilience in people with SCI we need to understand how they are storying (or not storying) SCI, and what these stories are doing (or not doing) in terms of resilience. Narrative is one way of achieving this.

### **Why narrative inquiry?**

Instead of a single, fixed, linear process narrative inquiry is best conceptualised as an overarching umbrella term. It accommodates a plurality of principals, philosophical assumptions and techniques which can be employed at different times and in different ways for different purposes. This gives rise to a diverse landscape which is further complicated by the lack of communication between different narrative approaches. As such, exactly what narrative inquiry is, as well as parallels and tensions between different methods can be difficult to untangle. However all approaches share a number of characteristics that make narrative inquiry suitable for the study of resilience in people with SCI. Narrative is both personal and social, narrative enables embodied engagement, narrative enables us to imagine alternate ways of living, and narrative brings ethics to the forefront of research by taking into account alterity and finalisation. These reasons shall now be discussed.

### **Narrative is both personal and social**

Narrative is both personal and social, taking into account both the psychological and sociological complexity (Crossley, 2003) of both disability and resilience. It does this by respecting the messiness of individual lived experience whilst at the same time allowing us to explore the ways in which this experience is shaped by common sense understandings and meaning structures in society. For example, narrative offers insights into the personal and social nature of both impairment and disability, helping us to understand how alternate ways of storying, negotiating and constructing impairment and disability can affect resilience (Goodley & Tregaski, 2006). Taking into account the personal and the social also enables the context of resilience to be displayed in great detail and clarity (Hauser et al., 2006), helping to illuminate different, and sometimes hidden examples of resilience. This is valuable as currently we know very little about resilience for people with SCI.

### **Narrative is embodied**

People tell stories about their bodies as well as through their bodies. Therefore impairment and the disabled body inescapably shape the story that is told (Frank, 1995). Narrative is therefore useful in the study of SCI as it links ‘the sensorial materiality of the body to wider social structures that shape the meaning making process at the individual and group level’ (Sparkes & Smith, 2011, p. 357).

As the body shapes our stories it also infuses all aspects of the research process, including our analyses. The researchers own body therefore needs to be recognised and accounted for in the research process. As narrative is about engaging with our bodies (Frank, 1995) it allows us to do just this. The researcher is able to reflect upon their bodies’ responses to their research and how their body is in turn shaping their research. Accounting for the body allows them to think about and question their views, which then enables them to be more reflexive about how they are representing the participant, and whether, for example, they are respecting alterity (Smith, 2008). This is not always an easy process, however, as even though we know that the body influences research we do not always know exactly how. To add to this, embodiment is also very difficult to put into words (Plummer, 2001). Representing embodiment through stories can help overcome this barrier.

Being an able bodied researcher studying a disabled population affected the research in a number of ways. Firstly, I was very anxious about being an able bodied researcher studying a disabled population. My main worry was related to how the participants would respond to me, in respect to whether they would question my motives for researching disability, and if so how they would judge these motives. For example, would they ask me why I was doing the research, and would they think that I was doing the research purely for my own benefit? Or for the benefit of aiding the spinal cord injured population? For this reason I entered the first few interviews with a lot of trepidation, which was observed by one participant in particular who immediately noticed my nerves and attempted to put me at ease by telling me jokes in an attempt to help me to relax. This affected the study of resilience in one of two ways, either the individual participant became more light-hearted in order to put me at ease, or it may have caused the participant to become more anxious or more serious during the interview due to the transference of emotion between myself and the participant. Over time my anxiety became less of an influence over the content and feel of the interview as I gained more experience and confidence in conducting interviews with spinally injured people.

Secondly, being an able bodied researcher studying a disabled population enabled me to ask ‘stupid questions’, or questions that someone with more knowledge of physical disability might not have had to ask as they may have had a greater understanding of the terminology surrounding spinal cord injury, as well as the experiences of spinal cord injured people. This affected the research as it meant that participants had to explain their experience in their own words and in greater detail than if I had had a greater awareness of the daily life of a spinal cord injured person, as well as the terminology associated with SCI. Furthermore, if the researcher had have been spinal cord injured, it is possible that they may have made more assumptions regarding the meaning of the participants’ words, or the practices that affected their resilience (such the content of a participants’ daily routine). In relation to this I also felt that I could explore the participants’ taken for granted assumptions. For example I could ask questions such as ‘why do you do this?’ and ‘how does that help you?’ This enabled a more detailed examination of how the participant constructed their resilience, especially on a day to day basis.

Thirdly, I felt that being an able bodied researcher studying a disabled population influenced the research process as it may have meant that I interpreted the participants’ stories differently than if I had have been disabled myself. Indeed, Oliver (1992) opposes able bodied

researchers conducting research on a disabled population as he contends that only disabled people know what it is like to be disabled and therefore only disabled people can accurately analyse disabled peoples stories. I do not see this to be the case, however, as by approaching this research from a constructivist epistemology, this piece of research aims to add one more level of understanding to the phenomena of resilience in people with SCI as opposed to aiming to uncover a singular ‘truth’.

### **Narrative enables the imagination of alternate futures**

A good life requires living well with stories. This is because stories are often behind both good and bad experiences (Frank, 2010). For example, the narrative template that once guided a person’s life, looking after them when they were able bodied may cease to care for a person when they become disabled, and may even be detrimental to their health and well-being. In order to live a healthy and happy life again people may have to adopt a new narrative template which takes care of them, helping them to show resilience. Narrative assists with this as it fashions a ‘kind of scholarship that seeks to practice a deep fidelity to the possibilities of societal and individual transformation, resistance and living life differently’ (Smith & Sparkes, 2008, p. 19). It does this by creating alternate stories, otherwise known as counter-narratives which help people to imagine other ways of living. For example, Swain and French (2000) counter the personal tragedy view of disability with a narrative (otherwise known as the affirmative model of disability) that views disability as a positive social identity. This helps to build both individual and collective resilience as it challenges and resists social oppression. Likewise, Smith and Sparkes (2004) use Frank’s (1995) chaos, restitution and quest narratives to highlight three very different ways of living with disability. This helps to promote resilience as the more alternate narratives there are to choose from, the more likely it is that a person can find a narrative that helps them show resilience. Moreover, if we know what narrative types aid resilience in people with SCI, we can then promote these narratives across this population. Narrative is therefore important in the study of resilience for people with SCI as through stories people can not only imagine alternate ways of showing resilience, but also share these alternate ways of showing resilience with SCI with others, helping them too, to show resilience.

## **Narrative puts ethics at the forefront of research**

It is imperative that any research does not harm the participants it seeks to help. This point is especially important to consider when studying resilience for people with SCI as both resilience and disability have the potential to be very sensitive topic areas. For example, when telling their life stories participants may delve into difficult times in their past, present, or imagined future. This has the potential to bring about distress which may be unnecessary, or even damaging. Thus, the topic of resilience for people with SCI should be approached with care. Narrative inquiry is desirable as it enables this by bringing ethics to the forefront of research through the consideration of alterity and finalisation.

Characterised as a person's otherness that precedes any attributes (Levinas, 2001, Frank, 2004; Smith & Sparkes, 2011), alterity maintains the space between people that is required for dialogue and storytelling. The main premise of alterity is that we cannot claim to know the other as we can never gain direct access to a person's inner experience. When a researcher inadvertently claims to know how the participant feels they deny that there is any difference between the participant and themselves. This closes down the space required for storytelling, violating alterity. This is a problematic as to infringe on the other's alterity is to commit symbolic violence against them (Frank, 2004). To avoid symbolic violence the researcher needs to be careful when trying to put themselves in another's shoes as empathy can be dangerous to alterity (Frank, 2004).

The concept of finalisation (Bakhtin, 1984) draws attention to how an author describes and writes about the other. It occurs when an author claims to have the last word about who another person is and who they can become. This prevents them from growing and changing as the researchers account becomes the character's fate. Space must be provided, allowing for the evolution of a narrative. This means that when characterising narratives as certain types care needs to be taken not to do so in a schematic, definitive way that doesn't recognise a narratives uniqueness, complexity and ability to change. As such, although a participant may show an affinity toward a certain narrative type, no individual story conforms entirely. People can draw from multiple types of narrative alternatively and repeatedly (Frank, 1995).

## **Sampling and participants**

The way in which participants are chosen partially makes what we find (Browne, 2005). As such, sampling procedures need to be taken into consideration as they invariably affect the quality of the research (Coyne, 1997). According to Miles and Huberman (1984), it is important that a sample is representative (i.e. it reflects ‘an instance of a general phenomena’ (p. 235)). This does not mean representative in a statistical way, but in a way that the research will resonate with people in this population, their families and those who work with them. This will increase the number of people who can find the research useful and accordingly increase the impact it has on peoples’ lives. In order to make sure the sample in this research is representative of the spinal cord injured population I need to select cases through which I can learn a great deal about issues of central importance to the purpose of the research (Patton, 1990), which in this case is resilience. These representative and information rich cases can be identified through the use of purposeful sampling (Patton, 1990).

In order to gain a deeper insight into resilience and how resilience is built following SCI I originally set out to purposefully recruit participants who had a high level of resilience and those who had a low level of resilience. One option was to screen individuals through the use of a questionnaire to measure resilience such as the CD-RISC (Connor & Davidson, 2003). However this is problematic for two reasons. Firstly, the questionnaire hasn’t been validated in people with a disability. Secondly, and most importantly, questionnaires may impose normative ideas of what is considered to be resilient behaviour upon the individual and therefore they may miss hidden examples of resilience. Additionally, unconventional examples of resilience could be mistaken for vulnerability. Instead, I found it useful to ask participants to evaluate their own level of resilience.

I began purposeful sampling by identifying participants whose stories I had heard about through the media, internet and my social network. As the study progressed, different participants were selected for different purposes (i.e. to explore different ideas/theories and gaps in knowledge). However, finding a representative, purposeful sample of information rich cases in the spinal cord injured population was hard to achieve. This was because people with SCI are hard to reach, due to the fact that SCI is relatively rare, affecting around 40,000 people in the UK (Apparelyzed, 2015). Women and older adults were harder still to reach due to the fact that most

injuries occur to young males between the ages of 16–30 years (Apparelyzed, 2015). For this reason snowball sampling was also used.

Snowball sampling worked by asking participants if they knew any other spinal cord injured people who may like to participate in the study. It was appropriate for a number of reasons. Firstly, snowball sampling provided a way of finding a hard to reach population. Secondly, snowball sampling worked as an inclusive technique as through word of mouth I heard about people with SCI who make up a minority of the SCI population (such as older women) and therefore may not be selected through a random sample due to their low numbers. Thirdly, I also heard about people with SCI who were not doing so well. It is possible that these people may not have responded to advertisements for participants.

I initially made contact with the participants through methods including email, telephone, face to face contact, through my own social network, online social networking, and internet forums. Face to face contact was used most extensively via access to a wheelchair tennis team and a wheelchair rugby team. With these participants I was able to explain the study, ask them if they would like to participate in the study and take their contact details in person. I also provided them with a sheet detailing more information about myself, what the study would entail and frequently asked questions. All of these people agreed to take part in the study. I believe meeting people like this aided recruitment as it eased any uncertainty people had in taking part in the study or my own legitimacy. This also made a good start to our research relationship. When I had to contact participants via email I sent them an initial email introducing myself, explaining how I had got their contact details, outlining the study and finally asking them if they would like to participate. The majority of participants replied and were happy to take part in the study. From here we used email to arrange a date, time and location for the interview which suited the participant. All of the interviewees except five invited me into their homes to conduct the interviews. As well as being convenient for the participants, conducting the interviews in participants' homes was useful as it provided a snapshot of how participants' lived with lives with disability (e.g. I watched both Trevor and Gareth cook meals). This sentiment was backed up by Margaret who replied in her email: 'It would be easier for me and it would also give you a greater insight into my life at home and the things I need.' Being able to see Margaret's home allowed me to understand the modifications she needed to her house and gave me an idea of the care she needed on a day to day basis. She also took great pride in showing me her photographs

and books, which I would not have been able to see if the interview was conducted elsewhere. I felt entering into people's homes gave me a greater feel and appreciation for the way that each participant lived on a day to day basis. As I could picture them doing things in their home that they described to me. To be in their own home also allowed the participants to be at ease in a comfortable and familiar environment, and enabled the interviews to last for as long as required.

The specific criteria for inclusion in the research were as follows: Participants were required to be a) over the age of 18, b) have a spinal cord injury and, c) live in the community (i.e. participants must have left hospital). To be able to explore the topic area I needed to use an adequate sample size. This had to be large enough to understand the diversity of experiences within the SCI population, but small enough to be able to analyse each case in the required depth and complexity. I approached this problem by not deciding on a sample size before I began, or how many times I would need to interview each participant. I instead carried on recruiting and interviewing until making the decision that I had sufficient information to fully answer my research questions. The participants included 19 spinal cord injured men and women (16 men and 3 women). Participants were aged between 24 and 65. A summary of participants' details is provided below (table 1).



**Table of participants**

Name	Age	Age acquired SCI	Level of injury	Living arrangements	Occupational Status	Number of interviews	Interview 1	Interview 2/3	Total hours interviewed	Time lining
Mitch	26	21	Tetra	Parents	Voluntary work	1	1:30		1:30	Yes
Tony	56	51	Tetra	Wife	Full time employed	2	1:30	1:15	2:45	Yes
Ronnie	49	17	Tetra	Wife and daughter	Voluntary work	2	2:30	1:50	4:20	Yes
Sammie	53	29	Walking	Husband	Self Employed	2	2:15	3:15	5:30	Yes
Mark	65	53	Tetra	Wife	Self Employed	2	4:10	4:45	8:55	Yes
Connie	49	24	Tetra	Alone with carers	Voluntary work	1	2:30		2:30	No
Chester	40	35	Para	Wife	Part time employed	1	2:15		2:15	Yes
Andy	32	23	Para	Girlfriend	Full time employed	2	2:15	1:55	4:10	Yes
Jack	36	24	Para	Fiancé	Funded	2	2:30	2:00	4:30	Yes
Chris	24	17	Tetra	Parents, sister and Grandma	Part time Student	2	2:55	1:30	4:25	Yes
Zac	40	19	Tetra	Wife	Full time coach	2	1:30	2:00	3:30	Yes
Daniel	26	21	Tetra	Mum and Brothers	Unemployed	2	0:50	1:05	1:55	Yes
Scott	30	18	Tetra	Wife	Funded	2	1:30	1:45	3:15	Yes

Name	Age	Age acquired SCI	Level of injury	Living arrangements	Occupational Status	Number of interviews	Interview 1	Interview 2/3	Total hours interviewed	Time lining
Trevor	40	19	Tetra	Alone	Unemployed	3	7:45	6:35	14:20	Yes
Nathan	37	24	Para	Girlfriend	Unemployed	2	1:25	2:30	3:55	Yes
Gareth	29	21	Tetra	Alone	Voluntary work	3	3:05	3:50	7:55	Yes
Sonia	35	29	Para	Husband	Voluntary work	2	2:30	2:15	4:45	Yes
Darren	46	24	Tetra	Alone	Unemployed	2	2:30	2:00	4:30	Yes
Joe	31	20	Tetra	Alone	Unemployed	2	1:35	1:20	2:55	Yes

## **Data collection**

Data collection for this study spanned a period of 29 months from April 2011 to September 2013. Across this time a combination of methods were used (interviews and timelines) concurrently to collect rich, storied data from the participants about their lives and experiences of SCI. This combination of methods was used in order to build up a nuanced, multi-layer understanding of the experience of SCI, mirroring the complexity of human experience.

## **Interviews**

Qualitative interviews are conversations in which a researcher gently guides a conversational partner in an extended discussion (Rubin & Rubin, 1995) with the purpose of obtaining information relevant to a particular research topic. Thus, interview data is a co-construction between the researcher and the participant and tied to the specific context of the interview. As I (the researcher) affect the data that is created, I had to think about how I approached the interview. I needed an approach that would elicit stories of resilience following SCI. This meant that I needed to be able to give participants space to tell their stories and let them evolve, yet at the same time making sure that these stories could help me answer my research questions. Because of this I decided to have two sections to each interview, with the first section being an unstructured life story interview, and the second section being a semi-structured interview.

The interview guide (see page 185) began with the question, could you tell me something about your life? The remainder of each interview guide focused upon more specific questions pertaining to resilience, disability and health and well-being. These questions were designed using my knowledge of existing literature (as well as gaps in the literature). I created a new interview guide specifically for each follow-up interview. These interview guides began with the question how are you? And what have you been up to since I last saw you? The remainder of the interview guides then focused upon questions which had arisen following each participants' previous interview, or questions which had transpired through the process of ongoing data analysis. Each participant was interviewed on 1, 2 or 3 occasions.

During each interview I employed the technique of active listening. This involved listening closely and responding to the participants spoken words, tone of voice, facial expressions and body language. At times I responded by paraphrasing what the participant had said in order to check for understanding, at times I responded with an acknowledgement of what

they had said (e.g. a ‘yes’ or a nod of the head), at times I gave them time to sit quietly if they were lost in thought, and at times I responded by asking them a question in order to elicit more information (e.g. who, what, where, why, how?). I endeavoured to ask open ended questions as well as to give the participant time to speak by not interrupting the participant or cutting them off. When conversation moved towards disability or resilience I wove in some of the more structured questions from my guide. Therefore, although I had planned to do the interview in two sections, in practice each interview was much more fluid. I ended each interview by asking the participant if they had anything else that they would like to add about their experiences, and thanking them for their participation.

I conducted a total of 34 interviews, each lasting between 40 minutes and 8 hours, with the majority lasting for approximately 2 hours. The interviews were transcribed verbatim as soon as possible after each interview using a ‘routine’ transcription technique (Sparkes & Smith, 2014). Following each interview I reflected upon the process of the interview and the interview data, recording my thoughts and feelings about the interview in a reflexive diary.

### **Timelining**

During each initial interview I gave participants an axis on a piece of plain A4 paper (see appendix). The top of the vertical axis was labelled with ‘highs’, the bottom with ‘lows’, and the horizontal axis with ‘time’. Participants then plotted different times of their lives on the axis with regard to how happy and healthy they felt. Some of the participants went through their lives temporally, whereas some of the participants began by plotting the most salient or memorable moments first (which often happened to be SCI). As participants were doing this they constructed rich narratives that were situated with regard to both time and a self-reported, relative level of health and well-being.

### **Methods of data analysis**

#### **Dialogical narrative analysis**

Viewing stories as *material semiotic companions* (Frank, 2010, p. 42) or ‘actors’, dialogical narrative analysis (DNA) (Frank, 2010) is a method of analysis that enables the researcher to look at what stories *do* by studying ‘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).

Whilst doing this ‘DNA’s concern is how to speak *with* a research participant rather than about him or her’ (Frank, 2012, p. 34, italics in original). In order to do this DNA has five methodological commitments which shall now be outlined.

DNA’s first commitment is that it recognises a person’s voice is not a singular voice, it is actually a number of voices that are in dialogue. This draws upon work by Bakhtin (1984) who wrote ‘two voices is the minimum for life... the minimum for existence’ (p. 252). This means that ‘a storyteller tells a story that is his or her own, but no story is ever entirely anyone’s own. Stories are composed from fragments of previous stories, artfully rearranged but never original’ (Frank, 2012, p. 34). The researcher’s job is therefore to try and identify the different voices in a person’s individual story.

The second commitment of DNA is to remain suspicious of monologue. In monologue ‘the hero is closed... he acts, experiences, thinks, and is conscious within the limits of what he is... he cannot cease to be himself’ (Bakhtin, 1984, p. 52). This is problematic as it imagines people within limits that define who they can be (Schutz, 1967). Rather than construct an objectified image of people, the aim of DNA is to witness stories and bring them together so that they have a more evocative voice and can be heard by others (Frank, 2012).

The third commitment of DNA is the recognition that stories have a symbiotic relationship with humans in that stories need us in order to be told and we need stories in order to ‘represent experiences that remain inchoate until they can be given narrative form’ (Frank, 2012, p. 36). As such, the very real sense of self we create through telling stories is constrained by the stories we have available to us.

The fourth commitment of DNA is that people remain unfinalised (Bakhtin, 1984). For Bakhtin this means that people can change from within and thus cannot be defined from the outside in any way that has the final word on who they are and who they can become. As such there is no ending and stories are constantly told and re-told in different ways. This makes it difficult to come to an ending in a research report. However, although the storyteller changes, the thing that does remain the same are the narrative resources available to the storyteller. It is this ‘stability of narrative resources—in particular, the finite number of character types, plot lines, and genres—allows research reports to draw conclusions and come to an end’ (Frank, 2012, p.

36). The fifth commitment of DNA is not to summarise findings but to enable people to hear themselves and others, as well as to respond to what is heard.

### **How do we practice dialogical narrative analysis?**

DNA involved thinking with stories as opposed to simply thinking about them. To do this the researcher needs to spend time indwelling, allowing the story to ‘breathe’ (Frank, 2010). In order to do this Plummer (1983) suggests ‘brooding and reflecting upon mounds of data for long periods of time until it ‘makes sense’ and ‘feels right,’ and key ideas and themes flow from it’ (p. 557). This process can be helped along by asking questions. These are questions such as how has the story been communicated? Why has the story been told in such a way? What is the story doing? And, who is it acting upon? To study the effects of the story the researcher needs to think ‘with’ stories, not merely about them. Thinking with stories requires ‘movement of thought’ (Frank, 2010, p. 72). In order to enable movement of thought, rather than offering a prescriptive procedure DNA offers a set of questions, and therefore can be seen as a ‘method of questioning’ (p. 71). For Frank (2010), the issue that informs all of these questions is:

*What is at stake* for whom, including the storyteller and the protagonist in the story, listeners who are present at the storytelling, and others who may not be present but are implicated in the story? How does the story, and the particular way it is told, define or redefine those stakes, raising or lowering them? How does the story change people’s sense of what is possible, what is permitted, and what is responsible or irresponsible? (pp. 74-75).

Thinking with stories in such a way is valuable as it allows the story to be understood in all of its complexity, revealing the multi layered nature of resilience and disability. A major way of practicing DNA I used was to write, as Frank (2012) explains:

The analysis of the selected stories takes place in attempts to write. The research report is not post hoc to an analysis that is completed before writing. Rather, reports emerge in multiple drafts that progressively discover what is to be included and how those stories hang together. In DNA, stories are first-order representations of life, and writing about stories is a second-order act of narrative representation. (Frank, 2012; p. 43)

Analysis therefore evolved over time by writing and re-writing possible chapters. This enabled me to really think about how I was representing the participants to prevent finalising them.

### **Criteria for judging the quality of the research**

In order to assess the potential utility of this research to inform the practice of resilience in people with SCI there will need to be a judgement made about its quality. This can often be difficult, however, due to the diverse and subjective nature of qualitative research. One way of accounting for the multiplicity and complexity inherent in qualitative research is through the use of criteria. Criteria enable the quality of qualitative research to be judged in relation to the specific aims of the individual study.

Best understood as lists of characterising traits (Smith, 1993; Smith & Deemer, 2000) that are open to reinterpretation (Schinke, Smith & McGannon, 2013), criteria for qualitative inquiry are ‘standards, benchmarks, and in some cases regulative ideals, that guide judgments about the goodness or ‘quality’ of inquiry processes and findings’ (Schwandt (1996), p. 22). Below are a list of criteria that I have endeavoured fulfil whilst conducting this research. It is upon these criteria that the quality of the research might be judged.

- **Substantive contribution:** Is our understanding of social life is aided by the research? For example, the research is informed by and adds to theoretical, empirical, methodological and practical knowledge in the subject area (Richardson, 2000; Caddick, 2014).
- **Width and rigour:** Is there evidence of comprehensive data collection/ analysis and theory throughout the research? For example, there are numerous and in depth quotations that support interpretations of the data (Lieblich, Tuval-Mashich, & Zilber, 1998; Caddick, 2014).
- **Coherence:** Does each section of the research fits together to create a flowing and meaningful account of resilience in people with SCI? For example, the methods used are suitable to answer the research questions and the study meets its aims (internal coherence), and the research embeds itself in existing literature (external coherence) (Lieblich et al., 1998; Caddick, 2014).

- **Worthy topic:** Is the area of research is pertinent, well-timed, important or stimulating? (Caddick, 2014)
- **Resonance:** Does the research influence, affect, or move specific readers through naturalistic generalisations, evocative representations, and transferable findings (Tracy, 2010).
- **Impact:** Does the research affect a person or group of people emotionally, intellectually or practically? Does the research creates questions, new lines of inquiry, or calls for action? (Richardson, 2000)
- **Ethical:** Have ethics have been taken into account and strong moral codes have been adhered to? (Caddick, 2014)

### **Chapter summary**

This chapter outlines the way in which I approached the study of resilience in people with SCI including my ontological and epistemological standpoint as a researcher, methods of selecting participants and data collection, method of data analysis, and finally the suggestion of criteria by which the research may be judged. The next section shall begin the analysis section by looking at what is resilience in people with SCI?



## **CHAPTER 4: What is resilience in people with spinal cord injury?**

### **Introduction**

This chapter will explore the meaning of resilience in people with SCI, highlighting the inherent difficulties in drawing a singular understanding of the concept. It will begin by addressing the participants struggle to articulate resilience, and suggest that the participants showed resilience through their stories. These stories were drawn from one of four different types of narrative existing ‘out there’ in society. These narrative types were the loss narrative, the adaptation narrative, the posttraumatic growth (PTG) narrative and the life-as-normal narrative. Resilience stories not only showed resilience, they also created resilience through their telling. When stories are told in the form of a loss narrative resilience meant the endurance of loss following adversity. When stories were told in the form of the adaptation narrative resilience meant adaptation to adversity. When stories were told in the form of the PTG narrative resilience meant growth from adversity, and when stories were told in the form of the life-as-normal narrative resilience meant living a life-as-normal despite adversity. These four understandings of resilience impact upon health and well-being in four different ways which will be summarised.

### **What is resilience in people with spinal cord injury, and how is it built?**

Participants suggested that it is very difficult for them to define the meaning of resilience due to the fact that they found the concept hard to articulate. Participants’ instead provided examples of what resilience was. Examples included: ‘*Strength of character*’ (Zac, interview 1), ‘*to be tough*’ (Mitch and Connie, both interview 1) and ‘*being strong and bouncing back*’ (Daniel, interview 1). Participants also provided examples through the use of stories. There were four different types of story that showed what resilience can be following SCI. These were stories of loss, stories of adaptation, stories of PTG, and life-as-normal stories.

Stories *do* things. Acting as companions they work with people, for people and on people, affecting what people are able to see as real, as possible, and as worth doing or best avoided (Frank, 2010). As such, stories did not merely *show* resilience, they also *built* resilience. The way in which each type of story showed resilience, as well as the way it built resilience shall now be summarised.

## Stories of loss

Stories of loss showed and built resilience through the storyline: *I lost a lot when becoming disabled, and I endure this loss*. When resilience was shown or built in this way it can be defined as: *Endurance of loss following adversity*. Darren provides an example of a story of loss:

Darren: It was a tremendous loss to lose the use of my hands. Oh, that was just serious, a serious blow and I often think what I'd be capable of doing now if I, you know, if I hadn't have had my accident and, I think I could have done quite a lot of stuff if I'd still been able bodied. Yeah, at the time it felt like there wasn't much left, the only thing that I had left was my life and that was it, or should I say the capability of still breathing at the time. It just felt like every possibility I had, had gone.

Jo: Do you ever feel any sense of loss now?

Darren: Oh yeah. Yeah. But I mean there's nothing you can do about it  
(Interview 2)

## Stories of adaptation

Stories of adaptation showed and built resilience through the storyline of: *Every day I am living better with disability*. When developed in this way resilience can be defined as: *Adaptation to adversity*. Chester provides an example of a story of adaptation:

What I've found is little things can cause such a big obstacle, if you go down a small path and people have got like the little boards outside the shops. They're an absolute pain, they take up most of the path, and you can't get past. Cars parking on pavements, if someone parks on a pavement, I've either got to go in the mud or I've got to go in the road, so you know its small things most of us don't even think about that can cause such a disruption in day to day activities. But I tend to try and explain to people in a jokey way, most people don't realise they've done something that's going to cause a problem... I try to stay positive when things are pretty grim to be honest. You can't dwell on what has been because you've only got now, you've just got to get on with it as it is now (Interview 2)

## **Stories of PTG**

Stories of PTG showed and built resilience through the storyline: *I have grown from the experience of disability over time*. When shown and built in this way resilience can be defined as: *Growth through adversity*. Sammie provides an example:

I'm quite a spiritual person I think, and to me life is a journey, you are meant to be learning lessons all of the way through it, and as you are learning lessons you are growing, developing, evolving. If you just stay in the same place and you don't challenge yourself you don't move out of your comfort zone you don't make any mistakes, so you're not going to learn anything, so you're not going to grow, and to me I just feel there has to be a purpose, and so that's why I keep doing that, and if the purpose is only just personal growth, that's a really worthwhile achievement for me, just to have one piece of understanding, something that clicks into place and I think all of that pain has been worthwhile because I now have this level of understanding (Interview 2)

## **Life-as-normal stories**

Life-as-normal stories showed and built resilience through the storyline: *Nothing has changed since becoming disabled*. When shown and built in this way resilience can be defined as: *Living a life-as-normal despite adversity*. Joe provides an example of a life as normal story: 'Nothing is that much different... I just struggle to see what people find so negative sometimes' (Interview 1).

## **Homogeneity and Heterogeneity**

Resilience has four different meanings in people with SCI and therefore resilience is heterogeneous. This is due to differences in individual characteristics, as well as the diversity of the spinal cord injured population. Participants had many different levels of injury, were treated in different spinal units and hospitals all over the world, and had acquired their SCI in various ways. Trevor elaborates:

Coming into contact with people all around the world with spinal cord injury, it's amazing how everyone differentiates and no one is exactly the same. You might

have the same injury and you might have the same level but everyone handles it in an entirely different way (Interview 1)

Thus, the diversity shown within the SCI population is vast. Not only were there differences in race, gender, nationality and socio economic status between participants, there were also differences in the physical level of injury, and differences in individual and environmental characteristics. Furthermore, the country that care is received may have an impact on a person with SCI. Darren explains:

If I'd had my accident in England I perhaps wouldn't have been damaged so much when the ambulance came and picked me up, because I knew my neck wasn't supported in any way when I was picked up. Now whether it (Darren's neck) was already severely knackered we'll never know, but when you break your neck abroad you have to expect these sorts of things (Interview 2)

Six participants were injured on holiday and thus didn't get the same level of care they may have otherwise received in the UK. Furthermore, often participants had to go through further adversity including language barriers, being away from their family, as well as waiting a long time to get home following SCI.

This highlights the fact that even though people are grouped together under the premise of having a SCI, they may still have very different levels of function and experiences of SCI. This resists the simplistic use of the social model alone to understand resilience in the SCI population. This is because by bringing disabled people together in order for political action, and moving the focus away from physical impairment, the social model essentialises people with a disability. Thus, it is important to consider *both* the similarities and differences between participants when trying to understand the meaning of resilience in people with SCI.

### **Homogeneity**

As well as being heterogeneous, the four understandings of resilience were also homogenous due to the fact that they shared one of four storylines. As well as this, the four understandings shared similarities with different conceptualisations of resilience from across the literature. This section shall outline each understanding of resilience and how it relates to the literature on resilience:

- *The endurance of loss during disability.* Parallels can be drawn between this understanding of resilience and existing conceptualisations such as ‘the ability to successfully cope with change and misfortune’ (Ahern, Kiehl, Sole & Byers, 2006, p. 104).
- *Adaptation to adversity.* This understanding of resilience is concurrent with the vast majority of ways of conceptualising resilience across the literature, for example it aligns with Luthar, Cicchetti and Becker’s (2000) definition of resilience as ‘a dynamic process encompassing positive adaptation within the context of significant adversity’ (p. 1).
- *Growth through adversity.* This growth-related understanding of resilience bears similarities with the definition of resilience used by Ungar (2004) of ‘positive growth and a successful life trajectory’ (p. 349).
- *Leading a life-as-normal despite adversity.* This definition parallels with research by Bonanno (2005) who suggests that resilience is ‘the maintenance of a relative stable trajectory of healthy functioning following exposure to a potential trauma’ (p. 135).

Viewing resilience as both homogenous and heterogeneous is important as it respects the premise that we cannot fully ‘know’ what resilience is in other (alterity) whilst at the same time acknowledging that resilience research can inform practice and policy across the spinal cord injured, as well as other populations.

### **The relationship between resilience and health and well-being**

The process of timelining, as well as stimulating the participants’ memories, was used to plot participants’ health and well-being across the course of their life. When all of the timelines were looked at together, they took one of two different trajectories. Seventeen participants followed the first trajectory (Figure 1), whereas two participants followed the second trajectory (Figure 2). When the trajectories were combined with participants’ stories of resilience (i.e. loss, adaptation, PTG and life-as-normal), the relationship between resilience and health and well-being could be understood. The timeline below (Figure 1) illustrates resilience stories combined with the first trajectory:

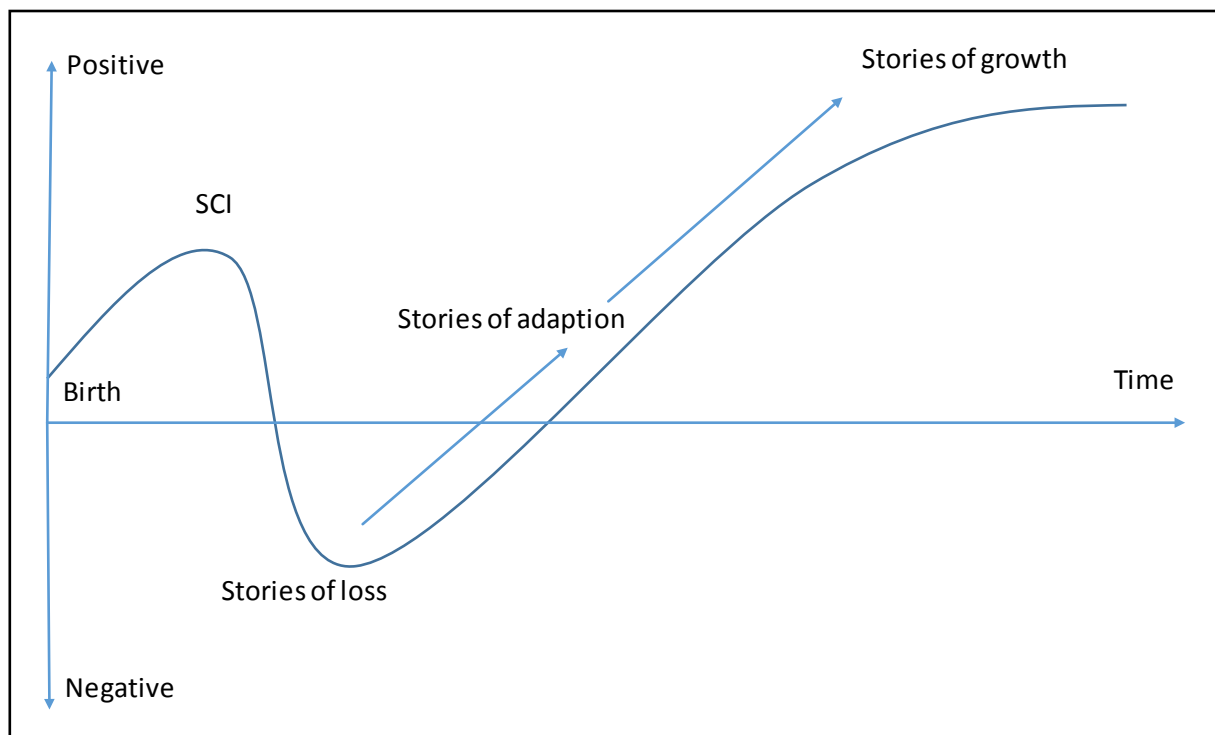


Figure 1: The loss, adaptation and growth trajectory combined with stories of loss, adaptation and PTG

The trajectory shown in Figure 1 was characterised by an initial steep linear downward movement following SCI, representing the loss of health and well-being. At this point participants' stories were in the form of loss stories. This was followed by a gradual increase in health and well-being up until a level comparable with that of pre-injury. At this point participants told stories of adaptation. At the point of interview health and well-being remained high or even exceeded pre-injury levels in some participants. When health and well-being exceeded pre-injury levels, stories of PTG were told. The second trajectory (shown by the dashed line) is as follows:

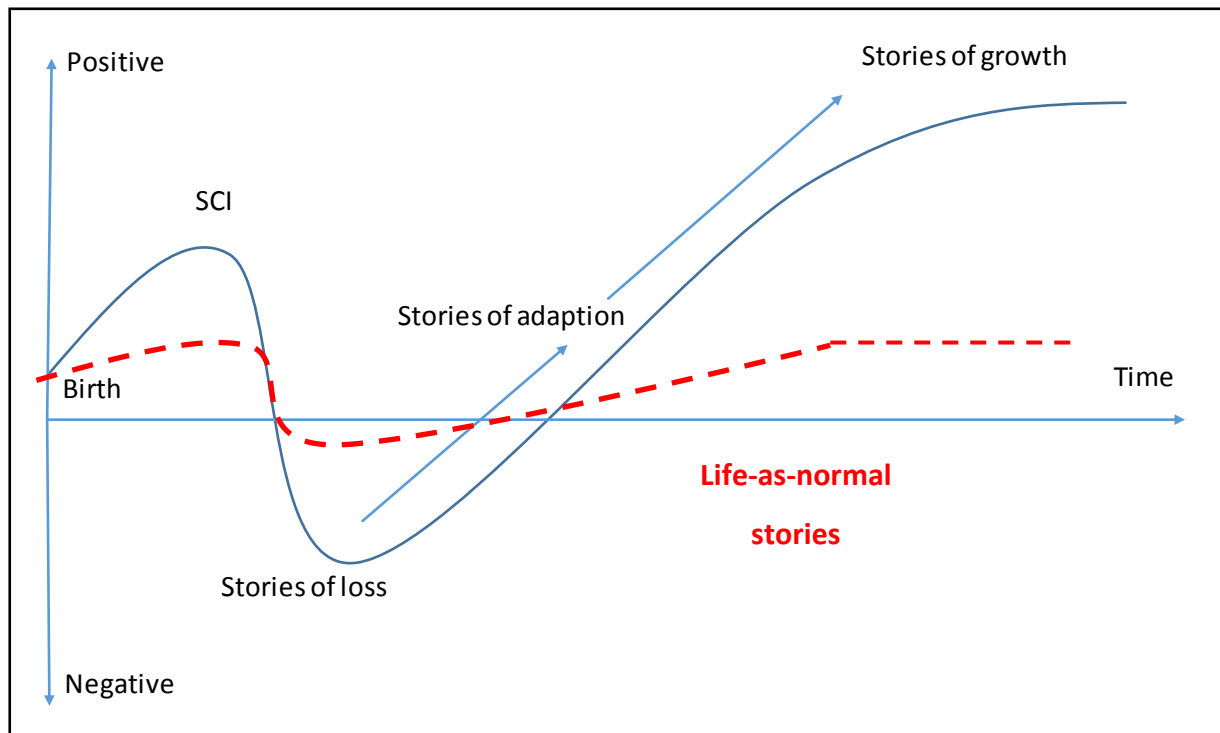


Figure 2: The life-as-normal trajectory (shown by the dashed line)

The life-as-normal trajectory followed the pattern of the first trajectory (Figure 1) in a much less pronounced way, staying closer to the line that represents neutral health and well-being. From beginning to end, this trajectory was accompanied by life as normal stories. To summarise, stories of resilience worked on resilience in the following ways:

- Stories of loss worked to stabilise a participants' low level of health and well-being, preventing it from falling any lower.
- Stories of adaptation worked to increase a participant's health and well-being up until a level comparable to that of pre-injury
- Stories of PTG increased health and well-being above and beyond pre injury levels.
- Life-as-normal stories prevented levels of health and well-being from falling too low, whilst also enabling participants to return to their previous level of health and well-being very quickly.

As such, although each type of story builds resilience, each type of story has a differing impact upon health and well-being with the PTG story having the greatest impact, followed by the adaptation and life-as-normal stories which have equal impact, followed by the loss story which has a negative impact upon health and well-being.

## **Summary**

This chapter has highlighted a number of things pertaining to what resilience is in people with SCI. Firstly, due to the intangible nature of resilience, participants had trouble in articulating exactly what resilience meant to them. Instead, resilience was shown through participants' stories of resilience. These were stories of loss, stories of adaptation, stories of PTG and life-as-normal stories. Each type of story showed and built resilience in four different ways, leading to four different faces or definitions of resilience.

In summary, this research builds on existing literature within this population in regard to resilience, health and well-being by suggesting that resilience is shown, built and therefore understood in four different ways across the SCI population with each of the four ways having a different effect on health and well-being. Different understandings of resilience are useful at different times and in different contexts following SCI (see practical implications, chapter 8).



## CHAPTER 4: The loss narrative

### Introduction

The loss narrative was used by participants in the early days, weeks and months (up until approximately 6 months) of SCI in order to show resilience. Two participants (Trevor and Jack), however, went on telling this type of story for a longer period of time and still lived by the loss narrative at the point of interview. This chapter shall unpack the main characteristics of the loss narrative, exploring what stories of loss narrative *show* and what they *do* in terms of resilience, disability and health and well-being.

### Loss

Loss is inherently part of being human (Scott, 2013). ‘Every transition in life is a loss of some kind as endings and beginnings are entangled: endings carry the potential of loss’ (Zwicky, 1991, cited in Scott, 2013 p. 249). This is especially so following traumatic SCI, which is described as one of the most devastating types of neurological impairment (Gill, 1999; Krause, 1998). The moment each participant realised the full extent of their injury and its consequences, they instantly lost the life that they had known, and which they had previously taken for granted (Dickinson, Allen & O’Carroll, 2008). This experience is known as loss of the nondisabled self (Yoshida, 1993). Jack illustrates:

I never chased what I had lost, I mourned it more than anything... and it was like I was mourning the death of me (Interview 2)

Loss of the nondisabled self or ‘loss of self’ (Charmaz, 1983, p. 168) refers to the ‘loss of core and peripheral aspects of the nondisabled self or the person prior to SCI’ (Yoshida, 1993, p. 224). For Darren this meant that he lost everything:

At the time it felt like there wasn’t much left, the only thing that I had left was my life and that was it, or should I say the capability of still breathing at the time. It just felt like every possibility I had, had gone (Interview 2)

One thing participants had left was access to the loss narrative. This narrative has the storyline: *I lost a lot when becoming disabled, but I endure it*. This plot was imperative in the process of resilience following SCI as it acted as a life raft to participants, keeping them afloat when they may have otherwise sank into *chaos* (Frank, 1995; Smith & Sparkes, 2004).

## **When are stories of loss told?**

Participants experienced a great sense of loss in the early stages of SCI when they first realised the extent of their injury and its consequences. For Sonia and Daniel this lasted only a few days, whereas for the majority of participants this lasted about 6 months following SCI. However, Trevor and Jack still told stories of loss at the time of interview. Jack provided an insight:

Jack: 'Everything that you do, any high that I ever have is always tinged with a thought in the back of my mind of "Yeah but, it's not like scoring a hat-trick on a Sunday morning is it?" It's always tempered by that. It's something I've not got past'

Jo: 'Do you think that will change?'

Jack: 'I'm sure it will as time goes on' (Interview 2)

Jack's excerpt suggests that although he still draws from the loss narrative to story his life he believes that this will change with time. Although this suggests a linear process, this is not necessarily the case. Sonia offered an example:

I'm going to have days where I shout and say, "Oh why can't I walk?" You know, or "It's not fair!" But I soon get over it and move on and have another good day the next day and forget about it (Interview 1)

Here, Sonia suggests that following SCI she has 'bad' days in which she locks into the loss narrative. Therefore, although a participants' life story could be framed by a particular narrative type, on a day to day basis the stories that they told depended on the context of their lives at that particular time. The next section shall explore stories of loss focusing on five aspects: Physical loss, loss of control, enduring pain, and the 'mask'. These five aspects highlight what stories of loss *show* and *do* in terms of resilience, disability and health and well-being.

## **Physical Loss**

The body is a necessary condition of life in as much as 'social life cannot proceed without this physiological substratum' (Twigg, 2002, p. 436; also see Crossley, 2001; Ellis, 2000; Shilling, 1993). Nonetheless, 'our organic body can be easily forgotten due to the reticence of visceral processes' (Leder, 1990, p. 69). However, following SCI participants' bodies' re-captured awareness when physical impairment restricted what participants could and could not do. This is

known as the 'dys-appearing body' (Leder, 1990). Participants' impairments often meant that they lost movement in their limbs. Due to this eighteen participants used a manual or an electrically powered wheelchair in order to help them get around. Although using a wheelchair helped to restore some mobility to participants, overall mobility was still restricted when compared to pre-injury levels. Zac provided an example:

Jo: 'So what's it feel like when you fall out of the chair?'

Zac: 'I feel Helpless. Having to rely on other people to help you back in the chair, I'm quite self-conscious, even now, I'm still quite conscious of myself. So if I was stuck, I can't because of the injury, I can't get back in the chair on my own so I just feel even more disabled I suppose is the only way I can say it.' (Interview 1)

When Zac falls out of his chair he can't get back into it due to the restrictions placed upon him by his body. This shows that impairment has a *direct* or *immediate* impact upon the lives of disabled people (Thomas, 2007). Furthermore, falling out of his chair also makes Zac feel more disabled than when he does when he is sitting up in his chair. Zac's story also shows how impairment makes him feel. This suggests that as well as being experienced as a physical characteristic 'impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning' (Hughes & Patterson, 1997, p. 335). These ideas are important as they challenge the social model's assertion that '*impairment* (characteristics of the body) could/should be separated from *disability* (social restrictions imposed on people with impairments)' (Thomas, 2007, p. 69). Impairment does have real effects upon participants' lives and therefore participants' resilience and health and well-being. This was especially so if the built environment was not accessible to wheelchair users due to uneven surfaces, high curbs, steps, and narrow doorways, or when other people restricted where participants could go. Mitch illustrates this restriction:

I went over to France on holiday and went to a restaurant and they wanted me to sit half inside the restaurant, half outside the restaurant because it wasn't big enough and I said "can I eat outside at the front on the seats out the front?" And they said, "No we don't serve food out there", I said "Oh can you make an allowance, cause I can't get in the restaurant" and so "Sorry I can't do it the chef

said no, I'm sorry”, and I got really annoyed so I just went flying into the restaurant and took out about three tables just to fucking make an impression (Interview 1)

Mitch’s excerpt illustrates a number of things. Firstly, although SCI did affect Mitch’s movement and mobility, it did not stop Mitch from eating at the restaurant and therefore isn’t what disables Mitch in this instance. Instead, structural barriers, and restrictions placed upon Mitch by others meant Mitch had to go and eat somewhere else. This environment was therefore oppressive and a cause of disability as it restricted where Mitch could go and therefore who he could become. Recognising disability as restriction placed upon people by SCI as well as the environment is important as it takes the focus of showing resilience away from people with SCI and places it on the interaction between the person and their situation (Lepore & Reverson, 2006).

Secondly, Mitch’s story shows he was restricted by another individual. This is known as psycho-emotional disablism. Defined by Thomas (2007), psycho–emotional disablism involves the ‘intended or unintended ‘hurtful’ words or social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments’ (p. 72). Psycho-emotional dimensions of disability (part of a social-relational approach to disability) are important as they provide a more inclusive account of how individuals are restricted than the social model alone (which only accounts for structural disablism).

Thirdly, this excerpt also shows how restrictions caused the build-up of negative emotions inside Mitch. This is another example of the psycho-emotional dimensions of disability. Mitch deals with these negative emotions by making ‘an impression’. For Mitch this is one way of showing resilience towards the situation he finds himself a part. However, it is unlikely that reacting is having a positive influence on Mitch’s health and well-being. Furthermore, it is also unlikely that it helps to challenge psycho-emotional disablism within society. Other participants also felt negative emotions (such as embarrassment, hopelessness, or feeling like they did not belong) however many dealt with them in a different way—through internalising them. This internalised oppression is when ‘individuals within a marginalised group in society internalise the prejudices held by the dominant group’ (Reeve, 2004), or as Morris (1991) puts it the acceptance and incorporation of ‘*their* values about *our* lives’ (p. 29; emphasis

in original). Internalised oppression is problematic as it affects how individuals think and what they do, as well as affecting their self-esteem (Marks, 1999).

### **Loss of control**

Loss of control of bodily function was the most salient loss following SCI, Jack explains:

If somebody said to me, you can walk again, or you can have bowel, bladder and sexual function, walking wouldn't even come near it. It would not come near it (emphasised). You know, and I think at first that would have been the craziest thing to hear me say, but that is true. As you live your life you think to yourself well do you know what, being in a wheelchair is not that much of a pain in the arse because you've modified your life to suit it, but bowel and bladder, they are something that you are constantly having to manage, monitor, battle with, make sure they are okay, then you've got your urine infections, you've got kidney infections (Interview 2)

As Jack suggests, the biggest loss following SCI often comes in the form of bodily function, especially of the bowel and bladder. One main reason why this was the case is due to the propensity of the human body to act unpredictably causing incontinence. Incontinence prevented participants from being spontaneous (Dickinson et al., 2008). Sonia explained:

We can't just do what we used to do, and we can't just jump in the car. We need to prepare, it's almost like you are a child. "Right, medi-bag, have we got this, have we got that? Well what if that happens, we need to pack a spare chair cover, a spare seat cover if you have an accident. Shall we take spare trousers and underwear and spare shoes?" There is like a long list of things you have got to think about. Before I think we liked doing things spontaneously, and there is definitely no spontaneity anymore in anything (Interview 1)

As Sonia alludes to, lack of control of bodily function can hold a disabled person back. As well as this incontinence also led to feelings embarrassment and denigration. For example Joe said '*You lose all self-decency as well when you first have the accident*' (Interview 1). Because of this sometimes participants tried to conceal the 'failures' of the human body (McIlvenny, 2003) by staying in their homes. Although this protected participants from psycho-emotional disablism it

was problematic as it had a negative effect on participants' health and well-being, and it did not challenge psycho-emotional disablism. Some participants instead chose to get on with their lives and accept negative feelings when incontinence did ensue. This was also problematic however as the acceptance of these feelings had a negative impact upon individuals' health and well-being as well as inadvertently enabling psycho-emotional disablism to continue. Overall, although the loss narrative helped participants show resilience to a loss of bodily function, it enabled psycho-emotional disablism and decreased health and well-being. Instead, psycho-emotional disablism needs to be decreased by narratives that challenge the normative cultural assumptions our society holds about the human body which emanate from our modern, sanitised, western culture (Charmaz, 1987; Goffman, 1963). See practical implications for a full discussion on how this can be done (chapter 8).

### **Enduring pain**

Disabled peoples' stories of pain have received scant research attention (Wendell, 1996; Barnes, Mercer & Shakespeare, 1999; Williams, 2000, Sparkes & Smith, 2008). This is surprising due to the fact that most participants experienced a great amount of pain when they first became injured, especially in the early stages of rehabilitation. Furthermore, this pain was not necessarily short lived, and many participants still experienced chronic pain at the point of interview.

Darren's pain has never subsided:

Jo:           What was the pain like then?

Darren:    I suppose the pain itself was like the sort of pain you get when you get a dead leg but all over your body at the same time. And you get something called, what I've been told to describe as "root pains". And that's when what works meets what doesn't. So for tetraplegics, it's like from just below the shoulders, all the way around. And that feels like someone's just got a knife and a belt and is tightening it and is tightening it and is tightening it so tight, and for a good few years, you're always sort of like struggling between the top and the bottom and it just feels horrendous. With the spasms, basically it just feels like you're in cramp all the time and there's nothing you can do about that. And then there's the sensation pain which I've never really lost in my

legs, and that basically just feels like all the skin's been scraped off with a cheese grater. So it feels, near enough all the time, my legs feel like they're on fire or being burnt. But I'm that used to it, it's just a different feeling these days. So, that's the best way I could describe the pain  
(Interview 2)

Darren's excerpt shows just how excruciating the experience of pain following SCI can be, describing his multiple different types of pain through the use of adjectives, similes and metaphors. In agreement with research by Corbett, Foster and Ong (2007), this pain can have a major effect on people's lives, in particular on a person's sense of self, and their plans for the future. In this way and in line with Stensman (1994), pain impedes adaptation to SCI. Sonia explains:

It's not my disability that debilitates me now, it's my pain. I feel that's the only thing that's sort of stopping me from being absolutely amazingly happy... My pain is debilitating, it's horrible and like I say that is my disability now. I say that because, that stops me going to meetings and it stops me doing things and generally, it just stops me doing what I want to do so yeah that is a big barrier  
(Interview 2)

The pain Sonia experiences penetrates every aspect of her being. This bears similarities to findings by Walker, Holloway and Sofaer (1999) who found that in those who experience chronic back pain, the experience of pain takes over their life. This is because pain episodes cause the body to come into the foreground existence due to a 'sensory intensification' (Leder, 1990, p. 71). However, rather than just being confined to visceral feelings, pain also has an 'affective call' which has the ability to compulsively 'seize' a person causing their whole life to be 'forcibly reoriented' (Leder, 1990, p. 72). As such, participants didn't have any other option but to live with pain in their present moment. As Leder (1990) notes, when people are in pain they are constricted spatio-temporally. This means that 'a person is no longer dispersed out *there* in the world, but suddenly congeal right *here*. Our attention is drawn back not only to our own bodies but often to a particular body part ... physical suffering constricts not only the spatial but the temporal sphere. As it pulls us back to the *here*, so severe pain summons us to the *now*' (p. 75). Thus, pain is often more debilitating in the moment it is felt than the physical impairment

itself. Participants had to contend with not only the direct experience of visceral pain but also the secondary complications of pain, for example pain often prevented participants from doing activities that would have increased their health and well-being. Pain therefore acts a barrier preventing participants from achieving optimal health and well-being. Participants like Darren learnt, however, to endure pain:

I don't really know if the pain ever really did subside, I think I just got more used to it. When I didn't notice the pain as much my body was in spasm all of the time so I didn't know whether I was in pain with the spasms or just in pain anyway, and I just didn't really think about it in that respect, it was just part of the journey that I was going on (Interview 2)

Accepting and then enduring pain was one way of building resilience. In order to do this each participant firstly had to show 'pain willingness' (Kratz, Hirsh, Edhe & Jensen, 2013). This pain willingness 'reflects how much an individual feels it is acceptable to allow, rather than attempt to control, pain'. This is imperative because participants were forced to live with, or constricted spatio-temporally by their pain. This means that 'a person is no longer dispersed out there in the world, but suddenly congeal right here. Our attention is drawn back not only to our own bodies but often to a particular body part ... severe pain summons us to the now' (Leder, 1990, p. 75). Pain acceptance is also important as it has been found to predict adaptation to chronic pain through the experience of less intense pain, less emotional distress, and better physical and psychosocial functioning (Gauthier et al., 2009; Kratz, Davis, & Zautra, 2007; McCracken, 1998; McCracken & Eccleston, 2003, 2006; McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999; Viane, Crombez, Eccleston, Devulder, & De Corte, 2004; Vowles, McCracken, & Eccleston, 2008). Furthermore, interventions grounded in pain acceptance have been shown to improve emotional and physical well-being and functioning (McCracken, Vowles, & Eccleston, 2005; Vowles & McCracken, 2008).

This much constant pain is unthinkable to most people. This is because pain is an embodied, visceral feeling, thus rendering it 'invisible' to other people (Hydén & Poelsson, 2002). 'Pain strikes one alone. Unlike the feel of the cool wind, pain is marked by an interiority that another cannot share... pain tends to induce self-reflection and isolation' (Leder, 1990, p. 74), dissociating the self from others (Smith, 1998, cited in Corbett, Foster & Ong, 2007). In



order to try and overcome this, participants endeavoured to share their feelings of pain through the use of words. This was often difficult for them, however, as pain is resistant to language (Scarry, 1985). This unspeakable pain (Sparkes & Smith, 2008) was made audible through the use of literary devices such as similes and metaphors, examples of which have previously been provided by Darren (page 69). Sparkes and Smith (2008) refer to this as the act of *naming pain*, and as they contend, it is these metaphors, adjectives and other linguistic forms that give pain a language and thus enable the subjective experience of pain to become speakable. It was through this process that participants constructed various meanings of pain and therefore made sense of their pain (Sparkes & Smith, 2008). As such, the loss narrative and dialogical relationships were imperative in helping participants' to show resilience following SCI. Although stories of loss sustained a participant's low level of health and well-being, this was not necessarily a bad thing as when levels health and well-being were sustained they were not falling any lower.

### **Loss of mental health**

Following loss of the nondisabled self, participants divided their lives into 'pre injury' and 'post injury'. This had one of two consequences. Firstly, at times it enabled participants to live a new life, directing their attention into the present. This meant that they were unlikely to make comparisons between their disabled self and their able bodied self, having a positive effect on the way they perceived disability, their resilience, and their health and well-being. Secondly, however, it also meant that at times participants could draw comparisons between their life now and their life before injury, highlighting exactly what they had lost. This feeling of loss led Trevor to fall '*lower and lower down in this big dark hole*' (Interview 1). Jack shared his experience:

Imagine what it's like to go to sleep feeling confident and yet waking up vulnerable? You're vulnerable and self-conscious. You're paranoid. You're unhappy about the way you look. All of these issues... I always just felt self-conscious, I felt unhappy at the way I looked, I had massive body issues (Interview 1)

Jack illustrates how becoming spinal cord injured has affected him psychologically, mainly due to a loss of self-esteem. Jack explained why this had occurred:

My self-esteem has always come from being so physically fit and good at everything I've ever done really, I'd be in the gym four or five, six times a week, plus playing football, plus playing golf, plus boxing, I'd always be doing something, and I think when you've spent your life with your self-esteem attached to the way you look it was a very difficult thing, and it still is now (Interview 2)

Following injury Jack lost self-esteem as he perceived that he has lost competence in domains of his life that were important to him, particularly sport and the way that he looked. As such self-esteem depends upon two components – *worth* and *competence*. Although this is in line with a dual model of self-esteem (Franks & Marolla, 1976), a two factor theory (Tafarodi & Swann Jr, 1995), or a multidimensional approach (Harter, 1999; O'Brien & Epstein, 1988), it differs from these approaches to self-esteem as it worth and competence were greatly affected by a participants' environment. Gareth provides an example:

I still look at myself as a kid cause I don't look at myself I am 29 I like a 21 year old when I'm talking to people and stuff I almost feel like below them in a way I almost feel like they are superior to me and stuff cause they can help me if I need help and they are a bit taller than me you know most people are like taller than me but now I am sitting down I do feel slightly inferior that is part of the reason I volunteer at a school I am doing a teaching course I think that is part of the reason I get along with kids I have always gotten along with kids I think now I feel I enjoy a little chat with them and have a little laugh with them and they don't like judge you they are interested in why your legs don't work I have no issues with that they will want to push you about and stuff I don't mind kids pushing me about they enjoy it that's one of the reasons I get along better with kids they don't make assumptions where some people do. I don't know why I feel inferior. I feel like it when I'm with family I can't lead the conversation or lead the group. I think people are always thinking is this going to be ok for Gareth this meal we have to make it it's good that they do that but it kind of makes you feel like I'm a child in that respect ... since the injury you feel like you're less than you were before. I feel good about myself in a way that I don't think I have an unattractive face and I don't think I'm a terrible looking guy– I think over time I have grown in my face more. I think I look better now than I did in university but I think my self-esteem

will never be as high as before the injury because you don't move much from below here (Gareth points at his chest). You're in a wheel chair all the time and it does affect you could be the best looking guy or girl in the world but since you are in wheel chair you're not like on eye level with everybody else. You've also got to worry about things like you can't be super confident cause things can go wrong, you can fall out of your chair and not get back up again or bowels can happen. I don't know it's just things like that that affect your self-esteem (Interview 1)

Here Gareth shows how his environment affects his self-esteem. When he is around children he feels competent and worthy because he feels like he is not judged because of his disability. However, when Gareth is around adults he sometimes feels inferior (another example of psycho-emotional disablism). Again, stories of loss helped Gareth endure loss of self-esteem and psycho-emotional disablism as they allowed him to make sense of his experience, as well as share it with others. Sharing his story is important as it challenges psycho-emotional disablism by opening people's eyes to the problem. If more people are aware of psycho-emotional and how they may be inadvertently causing psycho-emotional disablism society is better placed to combat the issue and therefore create resilience enhancing environments. A second way of enduring loss of self-esteem was to cut oneself off from others. Jack did just this:

Jo:           You said at first you were like "a prisoner in your own home", and just stayed inside, what was that like?

Jack:        A double edged sword really, great because it meant that I didn't have to face people, I didn't have to see people staring at me, or struggling up curbs, or anything to put me out of my comfort zone. But the other side of it was you were trapped (Interview 2)

For a while Jack could not endure the psycho-emotional disablism he was experiencing and instead withdrew from situations in which he might be subject to psycho-emotional disablism. Withdrawing from society meant that Jack was not able to share his experience of loss with others, or make sense of his own experience. This had a very negative impact on Jack's health and well-being.

Although research has suggested that following SCI that the majority of people experience depression (Bracken & Shepard, 1980; Gunther, 1971; Hohmann, 1975), only three

participants (Trevor, Jack and Sammie) described themselves as becoming depressed. The remaining sixteen participants did experience some depressive symptoms; however these symptoms were more akin to low mood and were generally confined to the early stages of admittance to hospital and rehabilitation. This is consistent with research by Shin, Goo, Yu, Kim and Yoon (2012) who have suggested that approximately 14% to 35% of people experience depression following SCI. Trevor describes his experience of depression:

You don't want to go on, you are in a very dark place, you just don't want to be around anyone, you don't care about anything, and you hate everything about yourself, and that's how I felt (Interview 1)

During periods of depression Trevor isolated himself from others and experienced a sense of self-loathing. As such, the experience of depression can cause a person to lose their sense of self, soul and spirit, marked by a feeling of emptiness, and a feeling of being cut off (Lupton, 1998). Although depression had a negative impact on health and well-being, for Trevor, Jack and Sammie depression provided a way, if not the only way, of enduring loss following SCI. Frank (1991, p. 65) explains: 'depression may be the ill person's most appropriate response to the situation.' As such, 'even fairly deep depression must be accepted as part of the experience of illness' (Frank, 1991, p. 65). That said, depression very nearly claimed Jack's and Trevor's lives in that it led both participants to contemplate or attempt suicide. Trevor painted a picture of his experience:

You just start blaming everything on yourself and I was just going lower and lower, down in this big dark hole. I was driving somewhere and felt as low as I possibly could have got to. So started driving and I started planning my suicide. I just thought, I always said that I would never do that, I always say that things could never get that bad that I wouldn't want to take my life. At times I had no strength, will power. I just didn't care about anything and thought it's gonna be so much better. I just thought it was the easy way, the best way off. So I was driving and just started planning, I thought how to do it and I thought about the note that I'd leave. I planned for a day and knew the day that I was gonna do it. I did it on the day of my anniversary when I broke my neck (Interview 1)

This excerpt shows just how debilitating a loss of health and well-being was for Trevor, endangering his very being. Unfortunately experiences such as this are not isolated and suicide is now the leading cause of death among spinally injured people under the age of 55 (Charlifue & Gerhart, 1991; Dijkers, 1999) with rates being two to six times higher than the able bodied population (Beedie & Kennedy, 2002; Fichtenbaum & Kirschblum, 2002). As such, it is not just the traumatic physical injury which is life threatening to the individual, it is also the on-going psychological effects that can too often accompany traumatic physical injury (Treischmann, 1988). Indeed, resilience may be unlikely in the face of multiple stressors (Lepore & Evans, 1996; Lepore & Revenson, 2006).

### **The ‘mask’**

Loss of social support included the complete severing of contact, or prior intimacy participants once had with family, friends, partners, and their wider community and culture. In order to prevent loss of support from happening participants engaged in emotional work. Although this was one way of showing and building resilience, emotional work of this kind often had a negative effect upon participants’ health and well-being.

Following SCI, all participants’ immediate family support either remained or grew stronger, and all but one participant (Mitch) stayed with their partners. The most prevalent type of relationship lost following SCI was that of friendship, for example Daniel lost his best friend:

When I was in hospital my best friend came to see me 3 times in 6 months so I was like don’t come see me don’t speak to me anymore (Interview 1)

Chris also lost touch with his friends:

Chris: It’s just surprising because I don’t think many of my school friends stayed in contact. So, I’ve got a lot of friends from just by being in a wheelchair, there are only a couple of friends from my school days who have stayed in touch...

Jo: You said none of your school friend kept in touch, why was that?

Chris: I don’t know I mean, I think because of my accident, I dunno, they may have found it difficult (Interview 1)

When Chris and Daniel acquired their SCI some of their friends found seeing them difficult to deal with. Disability created anxiety on the participants' friends' part, and then sequentially on the participants part, which once instilled made sustaining a relationship problematic. This was hard for many participants as friends provided an important network of support following SCI.

Although only one participant, Mitch, unwillingly lost his partner 6 months after SCI, all participants who were in a relationship at the time of interview (Sonia, Tony, Sammie, Zac, Scott, Jack, Ronnie and Chester) experienced a changed relationship with their partners. Sonia provides an example:

Me and Jay, we are not really, things are different, and things can get more fraught and stressful, but at the end of the day it's not going to be easy, it's not going to be a rose garden (Interview 1)

For Tony, Sonia and Ronnie this change meant their partner becoming their full-time carer. Although this can add extra pressure to relationships, all three participants were able to circumnavigate these stressors. Overall this meant that participants generally lost very little social support from pre to post injury. This contradicts the commonly held belief that following SCI people will lose their partners, Sonia explains:

If you know the statistics on it, I think there are more men that leave a spinal injured woman than more women that leave a spinal injured man, and I think that is really interesting. I think it is really high. It might be something like 80% of spinal injured women are left by their partner which is really bad... One of the, I won't say doctor's, because he wasn't a doctor, one of the people at the spinal unit, who shall remain nameless, said to my friend "Oh don't worry, your husband is going to leave you anyway."... And it's a stereotype and a generalization because luckily, for me Jay doesn't fit the generalization that most blokes leave the women (Interview 1)

Commonly accepted assumptions about the inevitable loss of social support following SCI influenced participants' behaviour in that participants performed emotional work so as not to lose their support. Although this was a way for participants to show resilience, it was problematic as it was detrimental to participants' health and well-being in that there were certain stories that they could not tell to others as they breached conventions about what is tellable and

untellable in society. Instead participants' presented themselves in a way that was socially desirable so that they did not lose the support of others. To many this came in the form of putting on a brave face or wearing a mask. Jack said: *'You get used to the mask don't you, you get used to being what people want you to be as opposed to what you are'* (Interview 2). Sonia explains why spinally injured people may wear this mask:

Sonia: Men have to put on a brave face more than the women. And it's a stereotype and a generalisation...

Jo: If someone was to put on a brave face, do you think that underneath that they might not feel so great about it?

Sonia: Definitely. I've done it myself. Well I went on a course on Saturday and pretty much everyone admitted that they do it because you're encouraged to at hospital... I would say all spinally injured people put on a brave face. Perhaps not all the time, but you usually want to paint a picture. And you want to paint a nice picture (Interview 1)

Following SCI it appears that many people perform emotional work in order to maintain appearance. This is an appearance which a 'society of healthy friends, co-workers, medical staff, and others places upon the ill (or disabled) person' (Frank, 1991, p. 64, brackets added). For example, when participants were first in hospital, even if the extent of their injuries could not be concealed they were still expected to convince their visitors that being spinal cord injured, or being in pain and discomfort wasn't that bad. Maintaining a 'cheerful patient' image is generally the minimal acceptable reaction to SCI and is praised by society as 'stoical'. The trouble arises when the disabled person 'may not feel like acting good-humoured or positive' as 'much of the time it takes hard work to hold this appearance in place' (Frank, 1991, pp. 65-66). Thus, there can be dangerous consequences to emotional work in that sustaining a cheerful image not only costs energy; it also costs opportunities to express what is happening in a spinal cord injured person's life so that life can be understood (Frank, 1991). For Frank (1991), attempts at a positive image diminish relationships with others by preventing them from sharing in the injury experience. This stoical image, or denial of suffering may not be what the spinally injured person wants or needs, 'but it is what they perceive those around them wanting and needing. This is not the ill persons own denial, but rather his accommodation to the denial of others' (Frank, 1991, p.

68). Over time this may result in the spinally injured person isolating themselves from others, Jack explains:

Jo:        You said you didn't really speak to anyone or see anyone, what was that like?

Jack:     I did my best not to. There is only so many times that you can answer the same questions, give people the same attitudes, try and say you know "I'm getting there, I'm alright." You just weren't you know, you can't spend every day thinking about killing yourself and then tell people that you are fine, it's just crazy

Jo:        What was that like, not being able to tell them?

Jack:     Stubborn pride in yourself isn't it, that's what stops you. And not being able to tell them. Well you have to understand that you might be able to say something once to somebody, but probably never again because human nature is such that they very soon tire of your company. They'll just come out with excuses at first, and after a while they won't bother with excuses they just won't bother staying in touch. That's how it works, no matter what anyone thinks. If you're not a nice person to be around, people won't bother being around you. It is that simple... Then whoever it is, or like me, you find yourself lonelier than you were in the first place (Interview 2)

Jack shows the problems of emotional work in that once Jack tired of maintaining the 'cheerful patient' or 'stoic' image he preferred not to come into contact with people due to the fear of rejection. 'What is needed in these moments is not denial but recognition. The ill person's suffering should be affirmed, whether or not it can be treated... "Yes we see your pain; we accept your fear" (Frank, 1991, p71). Frank notes:

Those who make cheerfulness and bravery the price they require for support deny their own humanity. They deny that to be human is to be mortal, to become ill and die. Ill persons need others to share in recognising with them the frailty of the human body. When others join the ill person in this recognition, courage and cheer may be the result,



not as an appearance to be worked at, but as a spontaneous expression of a common emotion (Frank, 1991, p71).

Although emotional work enabled participants to show resilience to loss, this way of building resilience should not necessarily be encouraged due to the fact that emotional work cannot always be maintained. Furthermore, emotional work also prevented stories of loss from being shared. This obscures the lived experience of disability from others, as well as isolates the disabled person, having a negative impact upon their health and well-being following SCI.

### **Summary**

This chapter has illustrated how the consequences of loss can have a greater effect on the person than the injury itself (Dijkers, 1999; Westgren & Levi, 1998), showing how astonishingly cruel loss can be when a person is suddenly ambushed by accident (Scott, 2013). Participants' stories of loss were characterised by 'dys-appearing' body, restriction, loss of mental health, and emotional work. Sharing stories of loss helped participants show resilience as well as helping others understand the lived experience of disability, helping to challenge psycho-emotional disablism. Moreover, stories of loss may help newly injured people as stories of loss gave participants some idea of what may lie ahead, as well as how to navigate what may lie ahead. Importantly, stories of loss highlight the fact that 'we should not romanticise notions of resilience. In particular, we must be cautious not to overly prescribe tonics associated with resilience, such as optimism, disclosure, and positive social exchanges' (Lepore & Revenson, 2006, p39). This is because loss is part of resilience in the same way that it is part of being human. Such losses, such as impairment effects are unavoidable, and others such as depression may be the only way of coping in certain contexts and times. These losses need to not be dismissed, or seen as the fault of the individual but need to be recognised and attended to. The next chapter shall explore adaptation, seeking to understand how it affects resilience and subjective health and well-being in people with SCI.

## CHAPTER 6: Adaptation

### Overview

Adaptation involved the increase of health and well-being back to a level comparable to that of pre-injury following SCI. This chapter shall unpack the main characteristics of stories of adaptation whilst exploring what stories of adaptation did in terms of resilience, disability and health and well-being.

### Adaptation

Adaptation was the storied process by which participants overcame loss to reach a level of health and well-being comparable to pre-injury levels. Stories of adaptation had the plot: *I live better with disability today, than I did yesterday*. Sonia provided an example:

I feel like I've gone through all the rubbish and now I can start to live again. I think between 2007 and now I've lost five years of my life. I've done really good stuff and there's been some really rubbish times, but I don't think I was living, I was just existing and now I feel like I'm back on track... I'm happy, really happy  
(Interview 2)

This chapter shall explore the main characteristics of stories of adaptation whilst looking at what these stories do in terms of resilience, disability and health and well-being. It is firstly important to point out that the adaptation narrative is scripted by the spinal unit before moving on to look at the main characteristics of the adaptation narrative which are regaining control, pain management, acceptance, humour, purpose, hope, social support, social comparison, and sport.

### Stories of adaptation scripted by the spinal unit

Although participants were grouped together by the fact they were all spinal cord injured, participants differed greatly with regard to their level of injury and therefore physical function. Furthermore, participants were rehabilitated in spinal units from all over the country. This would suggest that different participants might story the experience adaptation to SCI very differently. This was not the case however and the majority of participants (17) narrated their experience of adaptation in a similar way. Darren explained why he thought that spinal injured people narrate their experiences in very similar ways:

We're all in the same boat and we've all faced the same situations and so we're quite all used to the same sort of like terminology we've all come across... although we call them our own bridges to cross, it is the same bridge that a lot of people have had to cross. I think that's why you'll find so many similarities with the way things are described and stuff... it's the same terminology we use because there's only so many ways you can describe a certain thing, isn't there? And if we're all trying to achieve the same sort of thing then we're all going to be virtually using the same terminology (Interview 2)

This excerpt from Darren suggests that participants narrated their experience of SCI in a similar way due to the fact that participants' empirical realities were similar due to the fact they all had a SCI and there were only a limited number of ways to describe the experience of SCI. McAdams (2006) suggests that people selectively draw from a narrative menu in order to create stories that correspond with their embodied lived experience. These stories are then used to organise a person's experience as well as to narrate it to their selves and others (McAdams, 2006). This enables individuals and groups to make sense of, and find meaning in their experience. These menus are located out there in society, circulating in what Gubrium and Holstein (2009) term narrative environments. One characteristic of these narrative environments is that they 'support and value specific narratives while inhibiting or marginalizing others' (Perrier, 2013, p. 2090). The main narrative environment participants found themselves in following SCI was the spinal unit. The spinal unit made the adaptation narrative available to participants at the expense of the other three narrative types (loss, PTG and life-as-normal).

Beginning in hospital, or more usually a specialised spinal unit, comprehensive rehabilitation programmes were established for people with SCI as early as World War II (Guttman, 1979) in order to improve adaptation to issues of daily living. Chester provides an insight into the rehabilitation programme he undertook at the spinal unit:

Physio, occupational therapy, just basically lifestyle coaching, little things, you know if you've got to use a wheelchair showing you how to use a wheelchair, which I felt was very important. It's opened up a lot of avenues anyway, the spinal unit, ones that I wouldn't have got through the local hospital because there is no speciality... the experience through the spinal unit did give me a lot of confidence,

because they were the experts at it... they go through all of your medical, you know the practicalities of your condition, they talk about different effects of the damage to the cord. I've got neuropathic pain, constant, doesn't go away, and they look at different ways of managing that, controlling it. Talking about stretching, flexibility, posture. It's quite a holistic approach, it covers all aspects of day to day living, not just practical things, getting dressed, getting washed, but its little things as well, personal relationships, how to manage your day to day... skin management, skin care, bowel and bladder (Interview 1)

When participants entered the spinal unit their 'narrative map' (Pollner & Stein, 1996) did not account for their recent experience of SCI and their consequent feelings of loss. In order to promote the process of narrative reconstruction (Garro 1994; Good, 1994; Mattingly, 1994), professionals working in the spinal unit scripted the process of rehabilitation. They did this via the promotion of an alternative narrative map (the adaptation narrative). Over time participants gradually accepted this new narrative map which worked to guide them through rehabilitation in the spinal unit, through the transition from the spinal unit into the community, and then accompanied them through lifelong rehabilitation. All of the time stories of adaptation were showing and building resilience. Stories of adaptation did this in three main ways.

Firstly, upon entry to the spinal unit stories of adaptation showed and built resilience by preparing participants for the journey they were about to embark on. They did this by providing participants with a description of the people, practices, and problems they may face following SCI, as well as giving participants advice (Smith & Sparkes, 2005). This acted as a guide, helping participants through the process of rehabilitation.

Secondly, the stories of adaptation showed and built resilience by providing participants with a set of specific goals as well as timeframes for achieving these goals (Gubrium, Rittman, Williams, Young & Boylstein, 2003). Goals got progressively more difficult for example an initial goal was for participants to sit up in bed (aided) whereas a later goal was to transfer from a wheelchair into a car. The completion of goals promoted physical adaptation providing participants with a new bodily habitus (Bourdieu, 1977) or way of being in the world (Merleau-Ponty, 1962). Furthermore, goals also brought structure and meaning to daily life (Becker & Kaufman, 1995).

Thirdly, stories of adaptation showed and built resilience by instilling participants with a guiding set of ideas and philosophies (Ory & Williams, 1989). Sonia describes these ideas and philosophies as a *mantra*: ‘The mantra at the spinal unit was focus on what you can do, not on what you can’t do’ (Interview 1). This mantra averted participants’ attention away from loss and kept it focussed on the adaptation, promoting rehabilitation.

This section has highlighted the importance of the spinal unit in providing a narrative map (the adaptation narrative) for participants to live by and show and build their resilience. Although the adaptation narrative worked to increase participants’ health and well-being it foreclosed alternate ways of storying resilience following SCI (such as through stories of PTG or through life-as-normal stories). This is one reason why adaptation stories were the most common type of story told following SCI. The next section shall explore what stories of adaptation looked like following SCI.

### **Regaining control**

Following SCI participants lost the ability to control their body in the same way that they did prior to injury. Due to this participants’ stories of adaptation were characterised by participants re-learning how to control their bodies. This was done through the use of a daily routine which served the purpose of making participants’ bodies more predictable. Although this routine takes time and practice to construct, once it is perfected participants gained more control over their bowel and bladder movements. As such, a personal care routine helped participants overcome the loss of bodily function, showing and building resilience to loss. Sonia explains the significance of this:

I think if you ask any spinal injured person your life is dictated by your bowel management because you got to get that in order to organise your life around if you can get that sorted your more than half way there. I haven’t had an accident since mid-November– that is amazing and has had a great effect because you’re confident about going out and not have to worry about if anything is going to happen. It has taken me 5 years to get here (Interview 1)

This excerpt highlights exactly how important the management of bodily function is to Sonia’s life. When Sonia regained control her bodily functions she could leave the house without having to worry about incontinence (see page 68). This enabled her to live her life the way she wanted

to live it again. The way Sonia has learnt to manage her body, specifically her bowel and bladder care, is through the use of a daily routine which involves defecating at the same time every other day. This brings back a higher degree of certainty into Sonia's life, enabling her to regain a sense of control. Participants' daily routines were only fully established once participants had left formal rehabilitation in the spinal unit. Gareth explained:

Getting dressed took a lot of practice and learning your own way of doing everything, just learning. Because they teach you in the unit to do everything, but they teach you only one way and you have your own way. Everyone has to learn how to do things their own way differently and the way I get myself dressed now is very different from what you're taught on the unit and I gradually learned how to do things myself (Interview 1)

Gareth's excerpt suggests that rehabilitation continues to take place even once participants' have left the spinal unit and returned to the community. Sonia noted:

I think rehab does go on forever... I do feel that living in sort of the real world outside of the hospital you're always learning, you're always learning something new (Interview 2)

For all participants, physical adaptation continued once returning to the community as learning continued to occur, often through the use of trial and error. Yarkony, Roth, Heinemann, Wu, Katz, and Lovell (1987) also showed this, finding that ongoing adaptation led to an improved ability to perform self-care and mobility skills among patients with spinal cord injuries during an eight year follow-up study. As such, there is no end point for rehabilitation (Trieschmann, 1988; Kennedy, Marsh, Lowe, Grey, Short & Rogers, 2000). Here, rehabilitation does not imply cure, instead, it refers to 'long term recovery of, or adjustment to, functional losses' (Ory & Williams, 1989; p. 67). This section has suggested that the resilience that is shown and built by the individual (who works hard to establish a routine) and their environment (the spinal unit).

### **Pain management**

During episodes of pain it has been suggested that people feel, a) despair in their situation and, b) hope for future relief (Corbett, Foster & Ong (2007). In the current study however, rather than feelings of despair and hope for future relief, participants learnt how to manage/ control their

pain. Participants developed numerous and diverse strategies to help them do this, for example Ronnie found that being outside in the sunshine helped him where as sessions of acupuncture helped Sammie. As well as using pain killers, Sonia tried to keep busy when she was in pain:

I make cards and I do crafts and that is one of the things I do that helps my pain,  
'cause I get a lot of pain. I have spoken to a lot of people that have pain with spinal  
cord injury. Mine is like nerve pain, and I do know that it distracts me and it helps  
me, that distraction is really good (Interview 1)

Making cards and doing crafts distracted Sonia from her pain. Other distractions included activities such as having an occupation, volunteering, playing sport and spending time with family. This strategy is known as activity engagement and 'reflects the degree to which an individual engages in usual life activities, even with pain' (Kratz, Hirsh, Edhe & Jensen, 2013, p. 2). Aligned with the distraction hypothesis (Bahrke & Morgan, 1978), activity engagement helps an individual control pain due to the premise that attention to pain exacerbates pain, whereas distraction from pain lessens pain (Melzack & Wall, 1982). Distraction from pain built resilience as participants were not engulfed by their pain. Participants' had to be careful, however, for example if Darren did too much manual work in his house and garden it would cause him more pain. Sammie provided an example:

I did it the other day. I did too much because I just went mad on the cleaning front.  
And my husband kept saying to me," You're doing it you know, you're overdoing  
it. You should stop now, just stop that." I just had gotten a bit between my teeth,  
and I just carried on, and I paid for it for two days, I slept with a lot of pain, and  
just feeling really rough. So, I would, you know, it's a difficult one isn't it. It's a  
difficult one, managing yourself sensibly. I've never been very good at that. You  
know, I just throw myself at thing (Interview 2)

Sammie's excerpt illustrates the fine line between activities that helped participants control pain (showing and building resilience) and activities that actually exacerbated their pain (making it harder for participants to show and build resilience). Overall the control of bodily functions and the control of pain helped participants to begin to accept SCI.

## **Acceptance**

In order to adapt to SCI participants first had to accept their SCI and its consequences:

- Jo: Do you think you can ever fully adjust then with spinal cord injury
- Sonia: It's hard that. Yeah, I think you can, I think you have to and I think it's that acceptance and I think that's perhaps where I am at the moment. Where I have accepted everything and I have adjusted to everything and I'm ready to live my life, phase three, my new life. I've sort of been through the recovery period... I've got over it, it makes me feel better about myself because I have got through it and so it's hard to explain (Interview 2)

As Sonia shows, only once a person accepts their injury can they begin to increase their self-esteem and adapt to SCI. One way of showing acceptance was to celebrate SCI. Nathan celebrates his 'second birthday' every year:

I will never forget the 6<sup>th</sup> of October. That is the day I celebrate every year. It seems maybe morbid of my parents but they took pictures of my car and where I had the accident. It starts the beginning, it shows the road, then it shows the tire tracks, then it shows the corner, then it shows the car and the aftermath, then it shows me on day one in the hospital. I always look at them once a year and I think I have come a long way (Interview 1)

Here Nathan acknowledges his new life, rather than suppressing his emotions as is often done in contemporary society (Scott, 2013), helping him to accept disability. This suggests that 'there is a practical wisdom in containing loss, not trying to make it disappear but giving it expression' (Scott, 2013, p. 252). Such work can repair and rebuild lives (Scott, 2013), enabling participants to show resilience to SCI.

## **Humour**

Participants' stories of adaptation were often characterised by humour. Humour ensues when there is a 'discernible happening or an event; at least one person to perceive it; and possibly, although this is not essential, someone else with whom to share it' (Lefcourt, 2001; p. 28). Furthermore, 'somewhere in the perception of humorous events there must also be an element of



play, whether physical, or verbal' (Lefcourt, 2001; p. 28). As well as this 'humour itself is not a homogenous phenomenon but rather a concentration of expressions- some verbal, some nonverbal- that reveal a great variety of intentions, purposes and reactions' (Lefcourt, 2001; p. 55). Humour was used, mainly by the male participants, for two different purposes following SCI. The first way was to create social bonds, happiness and laughter. Joe provides an example:

He used to give me questionnaires and stuff to fill in. Three of us used to just think of the most stupid things we could write. The staff came to see us eventually... There were 2 old blokes at the top who were a good laugh and we'd just go and wind them up. They were both older, probably twenty or thirty years old. They must have been late 30's both big farm lads, we'd just go and wind them up all the time. That's what we did, just go and wind people up on the ward. Then we used to wind each other up. That's all it was (Interview 1)

As Joe suggests, male participants built relationships with other males through humour, and the enjoyment that they shared through it. Indeed 'the enjoyment shared with other men is highly valued but is also underpinned by the experience of being a man with other men' (Williams, 2009, p. 77). As well as for the use of pleasure, however, male participants also used humour as a coping strategy. Joe illustrates:

Jo: Do you think that the humour and the sarcasm helped you to deal with your injury?

Joe: Yeah, it's more of a defence mechanism really, my sarcasm. But that's all it was. I was in hospital with a few lads who were dead dry and that's all it was, you'd just sit there and wind people up... there was a lot of humour. The people that do struggle are the ones that are too serious (Interview 2)

As Joe suggests, humour helped him cope with SCI, by enabling him to detach himself from SCI (Frankl, 1969; Lefcourt, 2001). As such, humour can be seen as a 'liberating element' (Lefcourt, 2001, p. 61), allowing participants to put SCI to one side and thus avoid taking injury too seriously (Kelly and Dickinson 1997). Downplaying the significance of SCI alleviated participants' feelings of loss and as such humour can be summoned to relieve despair (Mulkay, 1988). Due to this, Joe believes that it is the people who don't use humour that struggle

following SCI. If it weren't for humour, more participants may have 'possibly become debilitated by the loss, succumbing to depressive forces' (Lefcourt, 2001, p. 61). It is for these reasons that humour builds resilience following SCI. The next section shall explore finding a purpose in life.

## **Purpose**

Trauma such as SCI disrupts a person's life, purpose in it and thus assumptive world (Danforth & Glass, 2001). Through the process of narrative reconstruction biographical disruptions are transformed into an event with a purpose (Warren & Manderson, 2008). Following SCI stories of adaptation reconstructed a participants' sense of purpose. Purpose in life came in many different forms, for example, sport, a job, a hobby, and relationships. Nathan explained how he regained purpose following SCI:

I got medically discharged from the forces and I was left no direction really. Although I had been disabled the thought of sitting down at a desk and sat on my back side, it didn't appeal to me at all. The only thing I was good at was sport, I wasn't good in school I did well enough to get by I didn't really try it didn't really appeal to me... When I first saw wheelchair rugby, I got in the chair and I loved it, basically got in the chair on the first day and I was in there all weekend... It takes over your life if you enjoy doing it you don't mind driving all over the place, like driving all the way down to London on a Sunday when your family is at a Christening. As soon as you start playing rugby you remember why you are there (Interview 1)

Resolution to a loss of purpose in life only occurs when the meaning of experience is restored (King et al., 2003) and requires the re-learning of the self and re-learning how the world works. For Nathan, finding a purpose through wheelchair rugby helped him to construct meaning, enabling him to go beyond any constraint that had been placed upon him (such as the dys-appearing body and physical barriers in the environment) to achieve satisfaction and fulfilment (Frankl, 1955) as well as both physical and mental health (Smith & Zautra, 2000). Participants created purpose in life by telling a new story about their life and life experiences, otherwise known as narrative reconstruction. Although Nathan was fortunate enough to be introduced to

his purpose in life during rehabilitation, for a number of participants finding this purpose took much longer, Jack explained:

Jack: I spent three years when I came out of hospital playing internet poker and doing nothing, and then you know basketball has really helped...

Jo: What do you think your life would be like without sport?

Jack: Boring for a start. I mean everyone needs something in life that fires them up, gets them going and gives them a passion to do something. I think life without a passion is life not worth living, in any form

(Interview 2)

Importantly this highlights that a purpose in life was a vehicle to adaptation, rather than an indication of adaptation. This means that it is important for newly spinally injured people to find a purpose in life as quickly as possible, so as to begin to adapt and avoid the continued feeling of loss. As Jack alludes to however, this can be difficult, despite that when given the opportunity, the individual will typically try to find positive meaning in response to disability (Dunn, 1994; 1996). Finding out what life experiences are important to an individual can aid finding a purpose in life and therefore builds resilience. Having a purpose in life also increased participants health and well-being as it enabled them to put their energy into activities that they were likely to gain benefits from (such as improved fitness or earning money), as opposed to dwelling on what they had lost following SCI. Having a purpose in life also instilled participants with hope for the future.

## **Hope**

Stories of adaptation were filled with hope. Hope can be defined as a 'multidimensional dynamic life force, characterised by a confident yet uncertain expectation of achieving a good future which, to the hoping person, is realistically possible' (Fitzgerald Miller, 2007, p. 13). Chris explained how a purpose and hope interact:

Family and rugby were two key things... I didn't know quite what I was going to do... I didn't really have a vision of what I wanted to do whereas now I can clearly see what targets I want... I haven't played in the elite squad yet but that's what I hope to do, what I'm working towards, it's an honour (Interview 1)

Chris illustrates three main points in this excerpt. Firstly he illustrates the relationship between purpose in life and hope, in that the purpose of playing wheelchair rugby for his country gave Chris hope for the future about what he might achieve. Secondly, this relationship means that hope can be developed and is therefore something to be cultivated over time (Neves, 2003). Thirdly, Chris hopes for a very specific, material goal of playing wheelchair rugby for his country. This is known as concrete hope (Marcel, 1962; Ezzy, 2000; Smith & Sparkes, 2005). Whilst telling stories of adaptation all participants illustrated the concept of concrete hope to describe their journey of rehabilitation. Smith and Sparkes (2005) believe that this kind of hope is related to the restitution narrative (Frank, 1995), which takes on the basic storyline of: ‘Yesterday I was able-bodied, today I’m disabled, but tomorrow I’ll be able-bodied again’ (p. 77). However, the participants in this study did not lock into the restitution narrative as instead they accepted that the level of ability they had prior to SCI would never be restored. Alternatively, their aim was to make their quality of life better, for example by moving to a more accessible home, or by finding a partner to share their life with. Although this suggests that adaptation is a type of restitution, the two narrative types differ in that participants in this study did not actively hope for a ‘cure’ to SCI to become available to them in their lifetime.

Hope was especially important as it enabled participants to live with uncertainty in so much that even though participants did not know that their current level of health and well-being could be sustained in the future, they still had the pervading belief that any adversity could be overcome. Sonia gave an example:

Things have got to be pretty bad to sort of affect me because you’ve had something so traumatic happen to you, nothing can ever compare to that feeling... The more crap you have to go through, the more you have to deal with makes you stronger, more positive, more like “come on I can handle anything, bring it on” you know, I’m strong (Interview 2)

As Sonia alludes to, hope comes alive when participants confronted testing times. It therefore provides a buffering effect when stress is high, and is negatively associated with distress (Horton & Wallander, 2001). Furthermore it is also central to the rehabilitation process (Warren & Manderson, 2008), providing a vehicle by which temptation to despair can actively be overcome (Marcel, 1962). Studies show that those individuals with higher hope undertake a higher number

of goals, more difficult goals, and remain more motivated to meet these goals in the face of adversity (Snyder, 1994) due to their heightened ability to problem solve and cope (Barnum et al., 1998). These people see their goals as a challenge and potential for success (Snyder et al., 1991). As such, hope builds resilience as it made participants more likely to strive towards, and meet their future goals in rehabilitation as well as once they returned to the community. The next section shall explore social support.

### **Social support**

The concept of social support has been useful in understanding the effects of environmental resources and social relationships on an individual's adjustment to stressful situations (Elliott et al., 1991) across numerous populations (such as the elderly) (Berkman, 1983; Cohen & Wills, 1985; Wallston, Alagna, DeVellis & DeVellis, 1983). The influence of a person's family and friends, both during their stay in the spinal unit, and on their return to the community was instrumental in helping participants tell stories of adaptation following SCI. Connie explained:

The support I got in hospital was unbelievable, and the people who came to visit me... we just have a good laugh really, when they come down it's not like I am paralysed. I'm just one of them again. When we are talking about the racing it takes all of the other stuff that you have to put up with, it takes it all away doesn't it. We have a really good laugh (Interview 1)

Following SCI support took a variety of forms, however, the main forms which related to a participants' resilience were emotional support and informational support. Sammie described her emotional support:

Jo: You said that you had quite a lot of close support around you as well, what kind of support is that?

Sammie: Well my husband is the main one, and I've just got my best friend who from an emotional support point of view is absolutely top-notch even though it's on the phone because she lives in London. We spent a lot of time on the phone together and that's where we were going to move to as well so I will see her a lot more. So yes, on the phone from her, and then when I was in hospital my sister came and brought me in food and

things, and I just had support from friends who just sent me nice e-mails and texts and things like that, so it's more emotional support. I don't actually get any practical support from anybody other than my husband, but then we don't need any. We do manage, its fine. I don't need any more than what I've got.

Jo: Yeah, what do you think it would be like without that kind of emotional support?

Sammie: Oh dear, you know just when you said that, just even trying to think about that just brings tears up because I mean the first thought that came into my head when you said that was well might as well die. So it is very important to me (Interview 1)

Here Sammie highlights the importance of having emotional support from her family, friends and partner. Relationships such as these contributed to participants' well-being because they provided a 'source of acceptance, intimacy, and confiding about emotions' (Wills, 1991, p. 273). This built participants' resilience as it meant that participants could share any negative emotions they had and therefore didn't bottle up feelings of loss. This enabled participants to begin to adapt to SCI. Furthermore, emotional support also came in the form of encouragement which inspired participants to progress through rehabilitation, bolstering resilience and health and well-being.

Another type of support participants received was informational support Chris received informational support from his peers:

You don't feel as disabled being in a wheelchair, you see guys who are going out and doing stuff, and it becomes easier to cope and adapt to your life, just by talking to those guys, like most of the guys I know have been disabled more than 20 years, I mean I've only been disabled 8 years now, because I've asked them personal things, because they already know all of your questions because they've been through that. So sometimes a lot the stuff that they are still wanting you to do (after you leave hospital), you do it when you get home, you just like talking to people in wheelchairs because they're in the same position as you about how you cope, and any questions you can discuss it with them (Interview 2)

By speaking to his friends who also had a SCI (especially those with a similar level of injury), Chris learnt suitable techniques that he could use in his everyday life to improve his physical function. This is known as informational support and was imperative in helping Chris to create a personal care routine that was suitable for his needs. As such, informational support built resilience as it provided participants with ways of dealing with the effects of impairment.

Aligned with previous research (Hass, Price & Freeman, 2013; Ljungberg et al., 2011; Blakeney, Herndon, Desai, Beard & Wales-Searle, 1998; Blakeney, Portman & Rutan, 1990), the prior examples of social support show and build resilience following SCI. Additionally, support leads to higher levels of self-worth (Barnum et al., 1998), physical health, mental health and longevity than those who do not perceive support (Cutrona & Russell, 1990; Hobfoll & Stevens, 1990). Social support also protects against depression and psychosocial impairment (Elliott, Herrick, Patti, Witty Godshall & Spruell, 1991). As well as being characterised by social support, participants' stories of adaptation were also characterised by social comparison.

### **Social comparison**

Social comparison theory is centred upon the idea that as human beings we have a 'drive for self evaluations concerning ones opinions and abilities' (Festinger, 1954, p. 135). This often has consequences with regard to how an individual feels and how they evaluate their situation (Buunk et al., 2006). Previous research has suggested that 59% of people with SCI compared themselves with others, with 25% of these people comparing themselves with other disabled people and 16% comparing themselves with nondisabled people (Schulz & Decker, 1985). However, this study found that every participant compared themselves with both disabled people and non-disabled people. This finding may be due to the fact that participants take part in quantitative studies they are reluctant to admit they compare themselves with others (Buunk et al., 2006) and therefore suggests that qualitative research may be better suited to eliciting people's experiences of social comparison. The effects of these social comparisons can be understood with reference to the direction of the comparison being made. This direction is concerned with the life situation of a participant in comparison to another and was upward, referring to someone who was in a more favourable situation than the participant in question, lateral, referring to someone who was in a similarly favourable situation to the participant in

question, or downward, referring to someone who was in a less favourable situation than the participant in question. Connie provided an example of social comparison:

The one thing when I was in hospital was the kids that were injured, 16 and 17 in car crashes and things like that, and you think to yourself I've been lucky because I was 31 and I'd had a really good life with the horses and I'd been in love so it all counteracts doesn't it. And you see these kiddies who are suffering from cancer and things; it starts to put life into perspective doesn't it? There is always somebody worse off than you (Interview 1)

As illustrated by Connie, participants often compared themselves to people (comparison targets) who were less fortunate than themselves such as those living with cancer, and those living in poverty in undeveloped countries. Nochi (2000) describes this as 'the self better than others' (p. 1797). Participants felt no identification (no similarity) with these people and instead felt like their lives were very different (contrasting). These differences were seen as positive by the participants as they perceived the comparison targets to be worse off than they themselves. As such, and concurrent with Wills' (1981, 1991) downward comparison theory, and the identification-contrast model (Buunk & Ybema, 1997), participants contrasted themselves with comparison targets who they perceived as worse off in order to maintain well-being (Van Der Zee et al., 2000). This process built participants' resilience as it enabled participants to concentrate on the positives in their lives as opposed to the negatives, as well as helping them gain a sense of perspective.

As well as downward comparisons participants also made upward and lateral comparisons with comparison targets. The most frequent comparison targets were those who had a similar level of SCI to the participant. This is in line with research by Buunk et al., (2006) who found that the most common type of comparison target people with SCI use are those with a similar health condition. Gareth offered an example of this:

I know a couple of people who are very similar kind of levels to me but can't do as much as me, and it's not something which hugely bothers them, whereas with me it would drive me crazy, it would make me determined to try. I can't say that these people don't try these things and don't try really hard but it feels like I wouldn't be able to just sit back and accept it in a similar way. When Louis started getting



stronger than me and faster than me at rugby it made me determined to try harder to get back my position type thing almost. Of all the people that are able to live independently and stuff after an injury, it made me determined that I could be one of those people (Interview 2)

As Gareth suggests, participants compared themselves to comparison targets with the same level of injury and thus a similar level of physical function. This is consistent with findings by Buunk et al., (2006) who reported that the most frequent comparisons people with SCI make are to do with one's physical condition. As Gareth's excerpt illustrated, this was especially so for those who played sport as participants often made comparisons with their teammates and opponents, especially comparisons related to the 'sporting body' (Sparkes, Pérez-Samaniego & Smith, 2012, p. 477). As such, 'people who most frequently compare their bodies to a particular reference group are those who use their bodies in a manner similar to the reference group members' (Franzoi & Klaiber, 2007, p. 211). These comparisons were generally upward. Sonia gave an example of an upward comparison:

I suppose the person I compare myself most to, she's a spinal injuries association mentor. And she used to come into the hospital to talk to people about their injuries and how to, she was a P.E. teacher when she had her accident, it was in the seventies and there was no laws and no rights for people with disabilities and they just ripped her contract up so she couldn't go back to work as a P.E. teacher so she transferred and did primary school teaching, but I like to think that I've got the same attitude as her, I feel like she's a really strong role model for disability and people with disabilities and I like to think that I'm sort of doing what she is doing, spreading the message and being a good role model to people with disabilities so I sort of compare myself to her, and I want to do as well as what she has done, she has retired now but she still does her counselling job, and so I also trained to be a mentor. Whereas she's a paid peer advisor, I'm just a volunteer peer advisor (Interview 2)

Here Sonia is comparing herself to a woman she identifies with and who aspires to be like. Participants compared themselves to a comparison target of higher physical ability when they desired self-improvement (Carmack Taylor et al., 2007). This upward comparison provided

participants with a role model to aspire towards and to seek information from (Carmack Taylor et al., 2007). This motivated participants to work hard during rehabilitation which in turn led to increased levels of physical capability (e.g. increased strength and fitness). This increased level of physical capability was illustrative of, and also built both participants' resilience and health and well-being as it allowed them to take part in a wider range of activities, as well as enabling them to become more independent. Again, this in line with the identification-contrast model (Buunk & Ybema, 1997) which suggests that well-being is maintained when people identify with those who are doing better than themselves (Van Der Zee et al., 2000; Sparkes, Pérez-Samaniego & Smith, 2012, p. 477).

## **Sport**

Sports participation was first introduced as part of rehabilitation in spinal units by Guttmann in 1944 due to the positive benefits he perceived it to have on people with disabilities. Guttmann's sentiment has since been backed up by extensive research (see Ashton-Shaeffer, Gibson, Autry & Hanson, 2001; Brasile & Hedrick, 1991; Brasile, Kleiber, & Harnisch, 1991; Greenwood, Dziewaltowski, & French, 1990; Guthrie & Castelnovo, 2001; Hedrick, 1986; Henschen, Horvat, & Roswal, 1992; Hopper & Santomier, 1984; Paulsen, French, & Sherill, 1990; Promis, Erevelles, & Matthews, 2001; White & Duda, 1993). Benefits of sports participation are thought to include the intrinsic satisfaction of taking part, the social bonds and camaraderie experienced, the social recognition from achieving excellence, enhanced physical preparation, and a 'heightened sense of self-esteem and personal empowerment that spills over into other social pursuits' (Berger, 2004, p. 802). These enrichments are not merely 'rehabilitative' or 'therapeutic,' they can be gained by any person who takes part in sport whether they be able bodied or physically impaired (Berger, 2004, p. 802).

Many sports have now been specially adapted to enable physically impaired people to participate. Thirteen participants took part in adapted sport (including wheelchair rugby, wheelchair tennis, wheelchair basketball, athletics and flying), with four of these participants participating at international level. Trevor redefined what sport meant to him when he went from playing able bodied rugby to wheelchair rugby:

The good thing about it is that I found out about wheelchair rugby. It was a huge thing for me because I needed to do have something to do. Where I love sports and

I love playing sports it was a massive thing for me to find something that I loved and was passionate about. Wheelchair rugby was that. I was so passionate about rugby and wheelchair rugby was the closest thing to rugby. So I just remember telling my mother that I was of sort of playing rugby again and she was freaked out: “What do you mean you’re playing rugby again. You just broke your neck playing rugby.” I said, “Calm down. It’s not like that. That’s why it’s called wheelchair rugby” (Interview 1)

In disability sport the people who play the sport and the people who govern the sport recognise physical impairment and adapt the sport so that people with different levels of injury, and different disabilities can play together. However, even though these adapted sports are physical and require great skill, many people still have trouble recognising people with disabilities as athletes, including people with disabilities themselves. This misperception is often due to poor media representation (DePauw & Gavron, 2005; Anderson, 2009). When disabled sports are given positive media attention they can serve to challenge both disabled and able bodied people’s perceptions of physical impairment. Scott explained:

Jo: Do you think the Paralympics changed people’s perceptions?

Scott: Ahh, massively, to this day people are still stopping me and recognising me from the TV, and they’re like “You’re the guy who plays wheelchair rugby”. They’re not treating you like you’re the guy in the wheelchair kind of thing, they’re like “You’re the athlete, wheelchair rugby player”, you know what I mean? And that’s amazing. Yeah so I get complete strangers stopping me and saying “You’re the guy off the telly, playing wheelchair rugby.” I don’t think it’s totally changed people’s perspective, do you know what I mean? But it’s helped massively and that’s a good thing because we want to be taken like the athletes that we are, and just like normal people, so you want them to treat you that way (Interview 2)

Here Scott provides an example of how being seen as an athlete helped participants to a) construct a positive disability identity (aligned with Swain and French’s (2000) affirmative model of disability) and b) challenge commonly held assumptions about disability in society.

High profile events such as the Paralympics are especially important in this process as they go some way towards placing disability sport on a level playing field with able-bodied sport, increasing its value, visibility and media coverage. Due to these reasons, stories of sport and of the disabled athlete were one way of showing and building resilience following SCI. However, as well as having the power to challenge the meaning of disability in society, stories of sport and the disabled athlete can also oppress disabled people (Shapiro, 1993). This occurs when the disabled athlete is portrayed as a supercrip. ‘Supercrips are those individuals whose inspirational stories of courage, dedication, and hard work prove that it can be done, that one can defy the odds and accomplish the impossible’ (Berger, 2008, p. 648). The rendering of disabled athletes as supercrips is thought to be oppressive for disabled people for a number of reasons. Firstly, the supercrip encourages unrealistic expectations about what people with disabilities can, and should be able to achieve, if only they tried hard enough (Berger, 2008). This not only encourages society to blame the individual for their disability but also suggests that viewing disability through the social model or a social relational lens is unnecessary as individuals by themselves can, and should be able to overcome barriers in society (Hardin & Hardin, 2004). Secondly, the supercrip promotes hegemonic masculinity and ableism. Ableism works by placing people with disabilities at the bottom of a hegemonically defined social hierarchy which assigns a higher value to ‘normal’ bodies (Smart, 2001; Hardin & Hardin, 2004; Berger, 2009). Finally, the supercrip works to reinforce the low societal expectations of people with disabilities (Iwakuma, 1997; Golden, 1992; Hardin & Hardin, 2004), reproducing a tragic image of disability (Berger, 2009). Thus, care must be taken to promote stories of the disabled athlete as opposed to the supercrip when building and showing resilience following SCI.

## **Summary**

The adaptation narrative (scripted by the spinal unit) is characterised by regaining control, pain management, acceptance, humour, purpose, hope, social support, social comparison, and sport. Telling stories of adaptation both showed participants’ resilience and built participants’ resilience as participants gradually learnt to live better with SCI. Telling stories of adaptation also bolstered participants’ health and well-being from incredibly low levels, up until a point in which was comparable with pre-injury levels. The next section shall explore the ways in which participants moved beyond adaptation and began to grow following SCI.

## **CHAPTER 7: The posttraumatic growth narrative**

### **Introduction**

Growth occurred when participants were able to experience development beyond that of adaptation following SCI. This chapter shall firstly introduce the concept posttraumatic growth before identifying when the posttraumatic growth narrative was used following SCI to tell stories of posttraumatic growth. This chapter shall then explore the characteristics of stories of posttraumatic growth, as well as investigating their consequences in terms of resilience, disability and health and well-being.

### **Posttraumatic growth**

In 1959, Victor Frankl (a survivor of Nazi concentration camps) documented his experiences in ‘Man’s Search for Meaning’, observing that those who were able to find meaning in life were also those more likely to survive the horrors inflicted upon them. He noted that while there was nothing inherently good in adversity, it might be possible to gain something out of adversity. He named this ‘tragic optimism’ and hypothesised that this arose from the acceptance that existence is transitory, and that suffering is inevitable (see Frankl, 2004). Now, over 50 years on, a growing body of literature confirms that growth from suffering is in fact possible, a phenomenon termed posttraumatic growth (PTG) (Tedeschi & Calhoun, 1995).

### **Stories of posttraumatic growth**

Following SCI all told stories of PTG. Stories of PTG were stories that had the plotline of *growth through adversity*. This meant that participants’ stories pertained to development above and beyond pre-injury levels. Sammie provided an example:

I’m quite a spiritual person I think, and to me life is a journey, you are meant to be learning lessons all of the way through it, and as you are learning lessons you are growing, developing, evolving. If you just stay in the same place and you don’t challenge yourself you don’t move out of your comfort zone you don’t make any mistakes, so you’re not going to learn anything, so you’re not going to grow, and to me I just feel there has to be a purpose, and so that’s why I keep doing that, and if the purpose is only just personal growth, that’s a really worthwhile achievement for me, just to have one piece of understanding, something that clicks into place

and I think all of that pain has been worthwhile because I now have this level of understanding (Interview 2)

As Sammie alludes to, PTG is the phenomenon of positive change through the experience of trauma and adversity. The main premise of PTG is that through the process of meaning making, people can grow beyond the limits set by others who have experienced a lower amount of trauma (Oakes, 2003) (see theoretical implications, chapter 8). In order to understand PTG and its effects on resilience and health and well-being we need to know when stories of PTG were told in people with SCI.

### **When are stories of PTG told?**

Participants told stories of PTG (and therefore showed and built resilience) about their current lives at the point of interview. Participants' stories of PTG arose in retrospect through being able to look back upon their lives and see how far they had come since their SCI. Sonia provided an example:

I really feel like I've gone from one place and I've stepped over a line and I'm in this new place. I think they do say it's about 5 years before you get back to, not wanting to use the word normal again, but get back to the person or the place that you want to be, but yeah, definitely a grieving process (Interview 2)

This account from Sonia is suggestive of stage theory research. However, this is not necessarily the case as it must be remembered that both loss and adaptation are ongoing. As such, as well as occurring *after* loss and adaptation, stories of PTG also occurred *alongside* stories of loss and adaptation. Sonia also provided an example of this when she said: 'I had a fantastic life, and I lost a lot, but I've also gained a lot from being injured' (Interview 2). This excerpt suggests that SCI can be storied as a loss *and* a growth, not necessarily one or the other. This is because in the empirical world the boundaries between stories are permeable. It is very difficult to know when stories of loss end and stories of adaptation begin and likewise when stories of adaptation end and stories of growth begin as stories distort the clear cut distinction. Moreover, two stories, such as adaptation and growth, or loss and growth can run side by side, constantly moving around. This makes it difficult to identify stories of PTG. In order to help identify stories of PTG their general characteristics shall now be unpacked.

## **What do stories of PTG look like?**

Although the different ways in which participants storied PTG were idiosyncratic, common characteristics of growth could be identified across participants. These included health work, strength of character, altruism and empathy, and appreciation. These characteristics shall now be explored in turn in order to a) understand what stories of PTG look like and b) understand the possible consequences of telling stories of PTG in terms of resilience, disability and health and well-being following SCI.

### **Health Work**

Following SCI participants were more concerned about their health and well-being and engaged in more health work. Health work refers to the 'wide range of practices that people engage in around their health' (Mykhalovskiy & McCoy, 2002, p. 24). Involving Schütz's (1962) notion of 'work' as 'purposive, embodied action that gears into the social and physical worlds surrounding any one individual' (Mykhalovskiy et al., 2002, p. 24), work is 'what people do that requires some effort, that they mean to do, and that involves some acquired competence' (Smith, 1987, p. 165). Zac gave an example:

Jo: Is there anything you do to look after your health then?

Zac: Yeah. I'm quite boring. I don't really drink, don't smoke. I eat well, I eat healthily, he says eating cake! I try not to put weight on and look after myself, especially now (Interview 1)

Gareth builds upon Zac's excerpt, explaining exactly why he looks after his health:

If I put on loads of weight or lost strength transfer would be a massive issue, I want to be out and I want to be able to do stuff, I don't want to get stuck on a hill or get tired. I want to be able to go on holiday and be fit and have the fitness to do stuff (Interview 1)

Sonia also added:

The most important thing is health and well-being, because if you've not got your health, you haven't got anything. So I think since my accident, that's been my main sort of concern. When I go to the groups they say oh why have you come to the group and I always say obviously I want to spread the disability awareness

word, but also my concern when it comes to disability is health and well-being and trying to make sure that people with disabilities have good health, and their well-being is looked after, you know psychologically or from every aspect (Interview 2)

As Sonia alludes to health work was not just physical, but also psychological, Sammie explained:

I've done an awful lot of personal development courses, I did some during my working life before I was an acupuncturist, and since then I've just paid and done a lot of courses, had a lot of counselling, which makes me sound (trails off), well I found counselling to be a very positive thing because I've found it very challenging. So there's that, and then I've done something called psychology of vision which is a mixture of psychology and spirituality which appealed to me at the time, which really helped me to understand myself, but I just read lots of different books. The one I've read recently is called asking the central question which is about a psychologist, it's using a psychologist who sort of identified the idea of a hierarchy, I suppose it's sort of a hierarchy of value I think, I can't remember the psychologist's name. So yeah that was really interesting and made me think about things in a different way so I'm always looking for something new out of something. To me the idea of just sitting and being is just an existence I don't want, so anything, if somebody recommends a good book to me, I find that's enlightening me, so yeah I'm interested in anything, being with the sorts of people who have got the same sort of approach as myself so my friends are quite deep people who want to understand what makes themselves tick and what makes the world tick (Interview 2)

All participants in the present study not only knew that they should care about their health, but also took steps to look after their health such as healthy eating, not smoking, not drinking too much and exercising. These findings are in contrast to Smith (2013) who found that spinally injured men cared about doing health work, 'but not too much' (p. 110). Sport was one of the main avenues participants used to perform health work, as Scott described:

I think obviously playing sport has helped me a lot, playing rugby because it makes you so much fitter and stronger, for instance if you took a tetraplegic who didn't play sport, didn't play rugby, and then took a tetraplegic who did play sport,



who did play rugby, I guarantee you the one who did play sport would have a much better quality of life than the one who didn't, it's a fact. I always say even if you don't want to play sport at the highest level, get involved anyway because it makes your life so much better, from just being fit and strong and healthy, and the social aspect of it, the pros far outweigh the cons. I've been back to the spinal unit to do peer support and I have people telling me "you're not a tetraplegic" just looking at how fit and strong I am, and how able I am (Interview 1)

As Scott suggested, both physical and psychological benefits can be gained from doing health work. Such benefits included greater ease at which everyday activities are performed, for example pushing a wheelchair is made easier due to decreased body weight, and increased strength and fitness. Furthermore, increased health work may also help prevent secondary health problems that people with SCI are more likely to encounter than the general population such as cardiovascular disease, pressure ulcers, and obesity (Soden et al., 2000). As such, health work contributed to a participant's resilience as it enabled them to do more in their lives due to increased health and well-being. The next characteristic of growth that shall be explored is strength of character.

### **Strength of Character**

Stories of growth following SCI were characterised by an increased strength of character. Sonia noted:

What has happened to me has made me a stronger person, definitely. Character building that's what me and my friends used to say, CB... everything is character building, all of your experiences are character building definitely, and you want to be a great character don't you? You don't want to be somebody who is just a blank, a nothing; you want to be somebody who is multi-faceted, like a sparkly diamond (Interview 2)

Here Sonia highlights how the experience of SCI has made her stronger and added to her character. Participants illustrated strength of character in two, often contradictory ways. The first way, known as the 'stoic' view involved having strength of character for its own sake. Connie described:

I just got on with it really, it's not been easy, but I was in a tough world, I was pretty tough to begin with, and it's about just getting on with it. It was (name of Connie's book) that came about when I was in hospital, and there was quite a lot of pain, moving my arms, and falling asleep with my arms up, and when I had to move them it was like owwww, and I just said to them "You can't hurt me, I'm a jump jockey, and jump jockeys don't cry" (Interview 1)

This way of showing strength of character was important for participants as strength of character alone suffices for a fulfilled life that is unaffected by unforeseen events (Nussbaum, 1994). This means that 'a person with great strength of character will not break down in the face of challenging external circumstances, however challenging they become' (Holmgren, 2004, p. 394). Showing strength of character in this way often required emotional work. This was beneficial for some participants' resilience (e.g. Connie's) as the performance of strength increased their feelings of self-worth. Emotional work, however, is not always beneficial and can have debilitating consequences (see page 72). At the other end of the spectrum, participants also showed strength of character by letting their emotions show, rather than being invulnerable to feelings. Trevor provides an example:

Someone who has one minute got everything going for them and next minute loses everything—and it's not whether or not you have a disability, no. You have an accident which causes you to have a disability, but it could be the loss of a family member, it could be loss of a loved one or a child, whatever the case may be... It would just be devastating for me because I'm that sort of person, I'm an emotional person, I'm a very sensitive person, caring I believe, and loving towards my family (Interview 1)

Although showing emotions made participants more vulnerable to external events (Harris, 1997), (such as the experience of SCI or the break-up of a relationship) it also enabled participants to experience a full range of emotions such as love, pleasure and pain. Letting these feelings show often meant entering into a dialogical relationship with another. As well as helping to build and maintain social support, dialogical relationships provided the space for the construction of stories that built resilience.

This section has shown that people can build resilience by being stoic as well as by sharing their emotions with others. Moreover, the pathway which has the biggest impact upon individuals' health and well-being depends upon the individual participant. For example some participants needed to be able to share their feelings with others (e.g. Trevor) whereas others felt stronger when they performed emotional work (e.g. Connie). Furthermore, the most beneficial pathway towards resilience also depended upon the situation, for example the stoic route was beneficial in situations where reaching the end goal had a better effect upon health and well-being than the journey towards that goal (i.e. stoicism was beneficial as a means to an end), whereas being able to share one's emotion was more beneficial in situations which the performance of emotional work would have been debilitating. However, it must be remembered that emotional work does not challenge psycho-emotional disability, or help non-disabled people to understand the experience of SCI. Taking all of this into account, it was useful for participants to make use of both of these pathways in order to build resilience following SCI as long as a) being stoic did not come at the expense of health and well-being b) participants were not stoic in the face of psycho-emotional disability. One way of exploring strength of character and how it contributes to positive development is to break it down into character strengths. This will enable an understanding of the specific strengths of character that are beneficial to resilience, disability and health and well-being.

### **Character strengths**

Character strengths involve the disposition to act towards recognisable human flourishing (Yearley, 1990). Although this suggests that character strengths are innate, this is not the case as character strengths are constructed through interactions between the individual and their wider cultural environment. As such character strengths are relational acts which are often deliberate and can be reflected upon (Park, Peterson & Seligman, 2004). As Aristotle first suggested, these character strengths are important as the enactment of one or more character strengths is fulfilling to the individual (Crisp, 2000). Thus, the study of strength of character and character strengths is important to the study of resilience (specifically stories of PTG), and health and well-being. The number of strengths that can be exhibited by a person is boundless, however, some strengths have more of an impact on life satisfaction than others (Park, Peterson & Seligman, 2004). Aligned with research by Chun and Lee (2008), appreciation was a salient character strength, associated with PTG in individuals with SCI. Appreciation shall now be explored.

## Appreciation

Appreciation involves an appraisal of increased preciousness or worth. Aligned with research by Chun and Lee (2013), following SCI many participants had a much greater appreciation for life, and gratitude for what they had, as opposed to what they did not. Indeed, a number of times Sonia repeated the line: ‘focus on what you can do, not on what you can’t do’ (Sonia, interview 1). Mitch talked about why he felt appreciation:

I look at myself as being very lucky and fortunate. It happened for a reason – why I’m still alive—and that’s how I get it straight in my head. And it’s like my purpose of how I can help other people in the same situation... I was very lucky that I had a family and friends (Interview 1)

Chester provided another example:

I’m quite lucky because I’ve got the car, all of the family support... I’ve been very lucky because I’ve managed to do so much, I’ve travelled the world, I was in the army, I’ve seen all of the experiences through working for the ambulance. When I went into rehab I was feeling quite sorry for myself and I went and I saw a young boy of 17 with a very high fracture, could just about move his arms and that sort of hit it home to me that I am lucky (Interview 1)

These excerpts illustrate how in the face of loss—and the sustained possibility of loss, participants acknowledged the value of their life and felt lucky for what they had. According to Janoff-Bulman (2004) this occurs because ‘we typically do not value the ordinary, but rather the extraordinary, which we somehow perceive as special. For survivors, life becomes special, because it can no longer be taken for granted’ (p. 33). This was also in concordance with findings by Chun and Lee (2008) who found that participants were able to find appreciation by concentrating on the small everyday pleasures. Mitch provided an example: ‘it’s the simple things, like to go out to the cinema or things... it’s worth doing’ (Interview 1). Similarly, this is in line with Oakes (2003) who found that taking small active steps helps people to feel more positively about trauma. Participants also tried to do as much as they could with their lives and live their lives to the full as they appreciated the transitory nature of human existence. Overall, increased appreciation showed and built resilience following SCI as well as increased participants’ health and well-being. This increased appreciation also built altruism as it made

participants realise that others weren't always as lucky as they were. The next section shall explore altruism.

## **Altruism**

Humans are heavily inclined to be altruistic (Fehr, Bernhard & Rothenbach, 2008; Fehr & Gächter, 2002; Warneken & Tomasello, 2006, 2009), often helping and sharing with others with no thought for themselves (Fehr & Fischbacher, 2003). This was especially so after the experience of SCI. One participant, Mitch began his own charity in order to help others:

I'm trying to focus all of my energy into other people with my new foundation and new charity... we've helped loads of other guys as well, so we trying to actively seek how we can help people, go out there and actually find people that we can help (Interview 1)

Connie spoke about trying to help others through her writing:

Connie: I try and help others through writing my books. You know if one person reads it and it helps them then it has done a good job

Jo: In what ways do you think it might help them?

Connie: Well just my perspective on life from what I've seen and the people that I have come across. And I've told some people who have said "well weren't you really annoyed?" and I'm like "no, I'm just pleased it happened to me." I've seen a few people who have really, really struggled with it (SCI), and a lot of people can't cope at all, they want a way out (Interview 1)

Following SCI participants wanted to help others in whatever way that they could (such as through raising money or offering advice). As such, the experience of trauma seems to have an immediate effect on altruistic behaviour (Li, Li, Decety & Lee, 2013). Staub's (2003, 2005) theory of 'altruism born of suffering' can be used to describe this form of altruism. The theory posits that 'individuals who have suffered may become particularly motivated to help others—not only despite their difficult experiences but precisely because of them' (Vollhardt, 2009, p. 54). Staub (2003) provided an example: 'Many people who have been neglected, physically or sexually abused, survived persecution, torture or genocide against their group, rather than

becoming hostile or vengeful against the world devote themselves in significant ways to helping others' (p. 540). Altruism was also beneficial to the participant:

I do quite a bit of peer support. I go into the unit weekly... if there was a tetraplegic that wanted to do the floor to chair transfers I would come in and show them how I did it... I used to do it at "Back-Up" charity as well; I used to go over to the Lake District. I used to teach wheel chair skills as part of "Back-Up" activity weeks, I loved it (Nathan, Interview 1)

Here Nathan is illustrating the 'paradox of happiness' (Phelps, 2001), or 'helper's high' (Walsh, 2011; Post, Underwood, Schloss, & Hulbert, 2002) often felt by people who volunteer their time and effort. Long since acknowledged by traditional spiritual schools of thought, this phenomenon posits that service and contribution can benefit both the giver and receiver (Walsh, 1999). This is in line with Becker's (1981) theory of altruism which posits that an altruist themselves also derives satisfaction from the well-being of others. Recent research has backed up this sentiment suggesting that altruism enhances characteristics such as love, joy, and generosity (Hopkins, 2001; Walsh, 1999), helping to create psychologically and physically healthier individuals who tend to live for longer than those who do not volunteer (Borgonovi, 2009; Grimm, Spring, & Dietz, 2007; Post, 2007). Moreover altruism is also associated with happiness and a reduction in symptoms of depression (Krueger, Hicks, & McGue, 2001; Musick & Wilson, 2003). Findings such as these are thought to hold strong across different cultural, economic and geographical settings (Kumar et al., 2012, p. 701).

In order to promote altruistic behaviour following SCI it is essential to understand the specific reasons (aside from personal satisfaction and well-being) why participants helped others. There were five main reasons why participants engaged in altruistic behaviour following SCI. These were a) due to increased empathy, b) an intrinsic need to make the world a better place, c) to give back to others in receipt of support, d) to find purpose and meaning in SCI, and finally, e) to promote disability awareness. These reasons shall now be expanded upon in turn.

Empathy can be seen as a 'vicarious, spontaneous sharing of affect' that 'can be provoked by witnessing another's emotional state' or 'by hearing about another's condition' (Keen, 2006, p. 208). Altruistic behaviour often arose from feelings of empathy participants had towards other people, particularly other people with spinal cord injuries. Mitch explained:

Being able to help people in the same situation really, and help them cope and share your experiences and knowledge and get them to think along similar lines to you but not, not try to give, not trying to force somebody into it but trying to leave an impression with them and leave a thought in their mind and trying to portray a positive image really (Interview 1)

As Mitch suggests in his excerpt, empathy is an underlying mechanism for altruistic actions (de Waal, 2008), instilling compassion (McMillen & Loveland Cook, 2003), and creating what is known as a wounded healer (Jung, 1951), or a wounded storyteller (Frank, 1995). The wounded healer's ability to help others is increased due to the skill, sensitivity and insight that they have learned through their painful life experiences. Furthermore, wounded healers are also more motivated to help others (Guggenbühl-Craig, 1999). Sonia was motivated to help others for different reasons:

I want to give a bit back for all the people that have helped me, and also I don't know, I suppose with my rose tinted glasses on I want the world to be the perfect place where everybody has opportunity and everybody is happy and you skip around with flowers everywhere (Interview 2)

Sonia engages in altruistic behaviour to try and make the world a better place for others, as well as to give back in repayment for all of the help she has received following SCI. Scott expanded on this point:

I get personal satisfaction out of it, because people were so good with me when I had my accident, like I was saying, the nursing staff, and other people like other patients and that were really good with me, so if I can repay that in any way then that's what I like to do because sometimes it can be a lonely world, do you know what I mean? People think that they're on their own sometimes, so if you can take five or ten minutes just to have a chat with somebody, it's actually amazing the amount that that actually lifts them. When you're gone it gives them a boost for the day, five or ten minutes of your time to speak to them, and people with appreciate that (Interview 1)

Participants like Sonia and Scott were grateful and often overwhelmed by all of the support they had received since being injured. For many participants this meant that they want to give

something back to others as a form of repayment, or to relay their own gratitude. Although this ‘reciprocal altruism’ (Trivers, 1971, p. 35) may portray altruism in a somewhat negative light, this is not the case as in terms of resilience and health and well-being it has positive effects on both the giver and receiver. Another reason people involved themselves with altruistic actions was related to meaning making. Sammie talked about why she supports other people on an internet forum:

It means that there’s some purpose in what I’ve been through, and nobody would ever want to go through. I’d never want to go through what’s happened to me. I don’t think any of the silver linings were necessarily worth the horror of what’s happened, but I need to find meaning in it. If me having lived through some of what I’ve lived through and experienced, I can then help somebody else as a result of that then it means it’s had some value (Interview 2)

Here, Sammie wanted to use her knowledge to help others so that her experience wasn’t in vein. Participants also tried to help others with spinal cord injuries through trying to raise awareness of disability. Sonia explained:

Because I’m disabled I can get the message across and hopefully improve disability awareness. Not just, not improve people with disabilities life, but also try and make people that are not disabled more aware of disability and that we’re not aliens and that we’re people who’ve had an accident or were born that way and we’ve still got a heart and a brain and blood running through our veins. So I think I just want to help people generally, improve their lives (Interview 2)

Here Sonia explains why she tries to raise awareness of disability within her community. Raising awareness of disability is something that many participants felt very strongly towards, going about it in different ways such as setting up disability awareness events or going out into the community and talking to people. This helped participants to feel as if they were helping the disability awareness movement to progress and that they were making the world a better, more equal place. Raising disability awareness built individual resilience as it enabled participants to feel like they were making a difference. It also created a resilience enhancing environment as it helped to reduce the number of barriers people with disability face in society. For both of these



reasons, raising awareness of disability helped increased the well-being of individual spinal cord injured people, as well as the spinal cord injured population as a whole.

In summary, even though it can be contested as to whether there is ever purely altruistic behaviour—of people giving for the sake of giving, altruism is important as following a traumatic experience ‘the more one forgets himself—by giving himself to a cause to serve or another person to love—the more human he is and the more he actualises himself’ (Frankl, 2004, p. 115). Although this kind of behaviour can be regarded as enlightened self-interest as opposed to self-sacrifice (Walsh, 1999) this doesn’t have to be seen in a negative light, especially where resilience and health and well-being are concerned. As the Dalai Lama put it, ‘If you’re going to be selfish, be wisely selfish—which means to love and serve others, since love and service to others bring rewards to oneself that otherwise would be unachievable’ (quoted in Walsh, 2011, p. 10).

### **Chapter summary**

When participants told stories of PTG they spoke about development above and beyond pre-injury levels. This chapter has outlined a number of ways in which participants storied this development. Characteristics of stories of PTG included health work, strength of character, altruism, and appreciation. This is in agreement with Tedeschi and Calhoun’s (2004) perspective that PTG is multifaceted and therefore cannot be reduced to a singular supportive environment, innate cognitive capacity, coping mechanism, form of psychological adjustment, measure of health and well-being, or any other similar construct. Stories of PTG helped build individual resilience as well as create environments that enhanced resilience. This had a positive impact on the health and well-being of spinal cord injured individuals as well as the spinal cord injured population as a collective.

## **CHAPTER 8: Life-as-normal**

### **Introduction**

Frank's (2013) life-as-normal narrative is used to explain how two participants' lives changed so minimally following SCI. This chapter shall explore the life-as-normal narrative in people with SCI, unpacking what life-as-normal stories look like as well as what they do in terms of resilience, disability and health and well-being.

### **Life-as-normal**

Although the impact of SCI is usually thought to be life changing, two participants (Joe and Daniel) felt almost indifferent (Nagler, 1950) towards SCI. Joe illustrated this when he said: 'Nothing is that much different' (Interview 1). As such, both Joe and Daniel experienced only a negligible amount of biographical disruption in comparison to other participants. This was because Joe and Daniel drew upon the life-as-normal narrative in order to tell their life stories following SCI. In order to understand how the life-as-normal narrative worked on resilience, disability and health and well-being we firstly need to be able to identify it from other narrative types. The next section shall explore when life-as-normal narrative was used to tell life-as-normal stories following SCI.

### **When were life-as-normal stories told?**

Following SCI both Joe and Daniel were able to begin to draw upon the life-as-normal narrative very quickly. For Daniel this occurred in the first few days:

I've never been down about my accident. I was sad for a few days. Then I just got on with it, my life... I am happy every minute and I have nothing to complain about, yeah I can't walk, but it's not a big deal, I can still do plenty of things  
(Interview 1)

This excerpt from Daniel shows that he only felt feelings of loss for a few days following injury, drawing from the life-as-normal narrative in order to tell life-as-normal stories almost immediately. Both men continued to tell life-as-normal stories over the course of their lives up to and including the point of interview. The next section shall explore the characteristics of life-as-normal stories, as well as how life-as-normal stories influence resilience, disability and health and well-being.

## **Characteristics of life-as-normal stories**

Life-as-normal stories have a number of definitive features including a) life-as-normal stories are simple, b) they reframe SCI, c) they depict a person who is 'laid-back', d) they enable participants to continue their previous activities, e) they involve no change in social support, e) they involve negotiating barriers, and f) participants who drew from the narrative were generally young and had few responsibilities or commitments at the time of injury. These characteristics shall now be discussed in turn.

### **Simplicity**

The first distinction between Daniel's and Joe's stories and other participants' life stories was their length and their level of complexity. Life-as-normal stories were very short and simple (note Daniel's and Joe's excerpts are generally very short). Joe provided an example:

Jo:            Could you start by telling me something about your life?

Joe:            At the moment? There's not much to say at the moment, I don't work,  
                    that's it really (Interview 1)

Daniel added:

Daniel:        I haven't changed I am really the same person like I said I just can't  
                    walk

Jo:            Yeah, but is there anything you have learned at all?

Daniel:        I've learned to drive, that's about it (Interview 1)

As reflected in these excerpts, both men saw their version of reality as simple and straightforward. This built resilience as it enabled both men to concentrate on being happy as opposed to spending time ruminating over SCI or over-analysing their lives. This was important as:

The happiest lives are often the simplest lives – externally, and especially internally. Happy people are too busy being happy and enjoying their lives to study their unhappiness. True, they feel unhappy from time to time, everyone does, but why study it? Acknowledging it and allowing it to pass away is all you really have to do (Carlson, 1993, pp. 175-6)

Thus, living life without many of the complexities that often accompany existence meant that neither participant experienced a great amount of loss, adaptation or growth following SCI. It must however be remembered that there could be an alternate reason for why participants told life-as-normal stories as opposed to stories of loss, growth, or sustainability. The short and simple nature of life-as-normal stories could also suggest silence:

Jo:           How do you think it (SCI) has affected your life then?

Daniel:    It hasn't really (Interview 1)

Although Daniel's excerpt suggests that his life has not changed following injury, his response could also suggest that he does not want to acknowledge the ways in which his life has actually changed. As Frank (2013) notes: 'I have learnt to respect silences but I have not lost my suspicion of what might be sustaining them and what their costs can be' (p. 197). Here, Daniel's silence could be an example of what Frank (2013) terms 'narrative abeyance' (p. 194). This is when 'preserving normality shuts down storytelling about illness' in that there is 'a story waiting to be told, but the moment of telling is not yet at hand' (p. 194). If this is the case then life-as-normal stories may be problematic as they may be preventing the telling of alternate stories (such as stories of loss, adaptation or growth). As such, although life-as-normal stories work for Joe and Daniel in terms of increasing their resilience and maintaining their health and well-being, care must be taken that life-as-normal stories are not masking narrative abeyance.

### **Reframing SCI**

Life-as-normal stories provide a way of reframing SCI from a traumatic event into an event that isn't so troubling. This minimised the effects of SCI on both Joe's and Daniel's lives. Joe exemplified this when he said:

I haven't had a hard life. I've never had anything put in front of me that has really troubled me as such. Like in my personal life there is nothing really that I can say has really tested me, there is obviously my accident, but that is dealt with because it has to be dealt with, there are no repercussions from that... You realise that nothing is that much different (living with SCI), it is different obviously, but it's a lot easier. Of course I'd change it if I could but not for the reasons why most people would. The only reason I'd change it for was it would just be nice to see

what would have happened if it never happened. It doesn't bother me in that way. I just struggle to see what people find so negative sometimes (Interview 1)

The term 'reframe' means to 'change the conceptual and/or emotional setting in which a situation is experienced and to place it in another frame, thereby changing its entire meaning' (Morse, 1997, p. 176). Participants used the process of reframing to tell their life story in a life-as-normal mode of telling. Aligned with previous research, this had positive effects such as lowering participants' distress (Fife, 1995; Ho, Chan, & Ho, 2004; Katz, Flasher, Cacciapaglia, & Nelson, 2001; Taylor, Lichtman, & Wood, 1984; Urcuyo, Boyers, Carver, & Antoni, 2005; Vickberg, Bovbjerg, DuHamel, Currie, & Redd, 2000; Vickberg et al., 2001), increasing participants' well-being (Carpenter, Brockopp, & Andrykowski, 1999; Curbow, Somerfield, Baker, Wingard, & Legro, 1993; Urcuyo et al., 2005), increasing participants' positive affect (Carver & Antoni, 2004; Katz et al., 2001; Sears, Stanton, & Danoff-Burg, 2003; Tomich & Helgeson, 2002), increasing participants' self-esteem (Lewis, 1989), and increasing participants' current and expected future life satisfaction (Curbow et al., 1993). Due to all of these benefits, reframing helped participants' foster resilience following SCI.

### **Placing disability in the background**

Life-as-normal stories helped Joe place SCI in the background of his life as opposed to the foreground:

I just manage to block stuff out... I just get on with it, and if it's bad news I'm like "Okay, it's done." There is no point in dwelling on it, what needs to be done next? (Interview 1)

Here, Joe does not deny SCI but positions 'it in the background, as much as possible for as long as possible...in order to preserve normality' (Frank, 2013, p. 195). Placing SCI in the background enabled both Joe and Daniel to stop any unproductive negative rumination especially in the form of any self-defeating or anxiety related thoughts. For many this could be seen as denial, however, 'dismissing these thoughts isn't the same as denial. You are dismissing your negative thoughts for one reason alone – to connect with your healthy functioning' (Carlson, 1993, p. 132). This was the first way in which placing SCI in the background showed and built resilience and maintained health and well-being following SCI.

Secondly, placing disability in the background also showed and built resilience and maintained health and well-being by enabling participants to accommodate their impairment (Gershick & Miller, 1995) in their life story, restoring participants' sense of coherence (SOC) very quickly. To accommodate impairment participants did not identify with impairment or sideline it either. Instead, in an attempt to make disability not matter, or ontologically unimportant (Watson, 2002) they were able to reconstruct their sense of what was 'normal' for them (Watson, 2002). By refusing to be categorised on the basis of bodily difference participants challenged ideas of normality (Watson, 2002). As such, the life-as-normal story helps to construct disability as a constantly evolving, unformed, unfixed concept, 'reflexively understood by the person in terms of his or her biography' (Giddens, 1991, p. 53). However, placing disability in the background can also be negative for people with SCI as individuals, and as a collective. For example if an individual places their disability in the background then they may overlook their disability, or not ask for help when help is needed. This may lead to the individual experiencing secondary complications of SCI such as pressure sores or urinary tract infections. Placing disability in the background may also have a negative impact upon the resilience and health and well-being of people with SCI as a collective as it may mean that people with SCI receive less help as others assume that help is not needed. Furthermore, placing disability in the background may also mean that instances of oppression are not recognised. As well as backgrounding disability rights, placing disability in the background prevented both Daniel and Joe from worrying, helping them to adopt a relaxed or 'laid back' attitude towards life.

### **Sense of self as 'laid back'**

Following SCI Joe and Daniel both described themselves as being very 'laid back'. Joe explains how this affects his resilience:

I'm resilient because nothing bothers me, it's not letting things get to you... I'm not the most enthusiastic of people, I suppose in a way people would be excited by something and I'm just like "alright, yeah". It's the way I am, I'm very dry and sarcastic it's who I am, I don't get overly excited about stuff, although I am, I just get on with it and if its bad news it's like "okay, right, it's done", no point dwelling on it (Interview 1)

In the second interview he added:

I've been told I have a lack of emotion, I'm very empty, I've been told that a lot. I'm laid back. I can't see the point of getting worked up or overly down or overly excited over stuff that you can't control. Basically when I had my accident I asked more questions than anything else rather than got stressed about it (Interview 2)

Joe's excerpts are concurrent with findings by Siller (1969) and Wittkower (1954) in that they suggest that people with passive personalities adjust better to disability. This was because a laid back attitude meant that both men accepted their lives as they were in the present and did not dwell on the past, or worry about the future. This enabled them to let go of their previous able bodied self and reconstruct a narrative that included disability with minimal upheaval, maintaining their resilience and health and well-being from pre to post SCI.

### **Continuation of previous activities**

One reason why the 'life-as-normal narrative declines to share illness experience' is to 'preserve other experiences' (Frank, 2013, p. 194). Daniel explained:

I just can't walk. I still have all the same friends, I still play sports and I still go out and drink—everything I used to do. I just can't walk and I can't go up steps  
(Interview 1)

Following SCI both Daniel and Joe continued with the same activities that they had done when they were able bodied and therefore only experienced a minimal number of transitions. This was important as it meant that Joe's and Daniel's assumptions about themselves and the world did not change (Schlossberg, 1981), enabling them to show and build resilience and maintain health and well-being following injury. Continuing with the activities that they had done prior to injury also meant that the majority of their relationships with the people closest to them did not change.

### **Unchanged social support**

Following injury both Joe and Daniel's network of social support did not change with their closest friends and family treating them in the same way as they had done prior to injury. Here is how Joe's friends reacted when he became injured:

Jo:           How did your friends react when you became injured?

Joe:           At first a few of them were a bit coy and quiet, but then they just reverted back to taking the mick... Nothing really bothers me, I've

always been around people that have been very blunt anyway, and a lot of people have the attitude, “It’s happened, get on with it (Interview 1)

Joe and his friends had always bonded using humour and this did not change once Joe became injured. Likewise, when asked about how his brothers feel about his injury Daniel replied: ‘They are alright, everything is the same. They are alright. Nothing has changed from that respect’ (Interview 1).

From these two excerpts it is clear that the support networks around both Joe and Daniel did not change following SCI. This helped them to show and build resilience and maintain health and well-being from pre to post injury as both men continued to receive the benefits of social support. As such, this is also an example of how Joe’s and Daniel’s social environment enhanced their resilience. Resilience enhancing environments such as these also enabled Joe and Daniel to negotiate physical, social, psychological and economic barriers within their community.

### **Negotiating Barriers**

Too often, ‘attempts to meet accessibility regulations have resulted in a profound lack of fit between the ideals of an accessible built environment and what is actually built for use by persons with and without disabilities’ (Gray, Gould & Bickenbach, 2003, p. 30). This creates barriers for people with SCI when they go outside into their community. ‘Barriers are people or things that obstruct or hinder a person with a disability from getting their needs or wishes met in a specific environment’ (Tighe, 2001, p. 517). This is important as the social model posits that it is such environmental barriers that are actually the cause of disability and not physical impairment itself (Oliver, 1990). Daniel talked about negotiating the physical barriers in his community:

Jo: Does it ever affect you when you can’t go up steps?

Daniel: I suppose it does, but you get around it, like you would a curb. Or you get an elevator (Interview 1)

As Daniel alludes to, although he does come across barriers in his environment, telling a life-as-normal story enables him to negotiate these barriers as opposed to being held back by them. By being able to overcome these barriers, and find new ways of doing things Daniel’s resilience is shown and built and health and well-being is maintained. Furthermore by overcoming barriers



Daniel is helping to surmount the ‘negative disability stereotype’ (Tighe, 2001, p. 526) in society. Overcoming barriers, however, can also be a potential issue to people with SCI, especially from the perspective of the social model and social-relational model as it deflects attention away from the way in which people are disabled by barriers in society.

### **Age and life circumstance at the time of injury**

Both Joe and Daniel were young at the time of injury with few responsibility or commitments. Joe explains the significance of this:

Having my accident young and being in hospital with a lot of older people you see the difference in age. For a lot of people it’s the lifestyle they had before the accident which affects them. A lot of people who are older and a bit more successful seem to really struggle with it for some reason, I don’t know why, but you they can’t be bothered to do anything and “why has it happened to me?” and stuff like that. And you get the younger people and it’s like “well this has happened, what I do to get the best out of my life?” A lot more driven, but I suppose in another way I didn’t have anything to lose, I was 16, I’d just left school, I didn’t have a job to lose, I didn’t have a mortgage, house, family, or anything like that so I think older people have a lot more to lose, they’ve got their family, they’ve got their job, and I think lots a lot more weight on them, as well as having the injury... I was lucky that I became injured so young that I had no responsibilities or commitments, I hadn’t really lived, therefore I had nothing to lose and nothing really changed (Interview 1)

This excerpt illustrates three main points with regard to life-as-normal stories and what facilitates their telling. Firstly, it highlights the importance of age at the time of injury in facilitating resilience through the telling of a life-as-normal story. Both Joe and Daniel were injured at a young age. This meant that their sense of self was still evolving and not as entrenched as it may have been if they had been injured later in life. In this respect, the malleable and open ended nature of these two men’s life stories at the time of injury enabled them to rebuild their identity much more easily, allowing them to accommodate SCI into their lives with less upheaval than many of the other participants. This made it much easier for both participants to maintain their resilience from pre to post SCI.

Secondly, it also shows the importance of a participant's life circumstance at the time of injury, with the most salient aspects being a participant's level of responsibility and number of commitments. Neither participant had great responsibility at the time of injury, with Joe still living at home and Daniel at University. This meant that both men were relatively free and open to changing their future plans. Therefore, they had very little narrative reconstruction to do when SCI occurred enabling them to tell a life-as-normal story from pre to post injury.

Thirdly, it also shows the importance of the amount of time that has passed since becoming injured. With becoming injured so young, both of these men have lived a high proportion of their lives with SCI. This means they have fewer memories of their able bodied selves to compare their disabled self to. In brief, being young and relatively commitment free at the time of injury enabled both Daniel and Joe to tell life-a-normal stories. This suggests that telling life-as-normal stories may be more difficult for older participants, or participants who had more responsibilities and commitments when they became injured.

### **Chapter summary**

In brief the life-as-normal narrative helped two participants (Daniel and Joe) to place SCI in the background and carry on with their lives in virtually an unchanged manner. Both men were able to begin to do this within the first few days following injury and continued to draw from the life-as-normal narrative to the point of interview. Life-as-normal stories can be identified by the fact they are simple, b) they reframe SCI, c) they depict a person who is 'laid-back', d) they enable participants to continue their previous activities, e) they involve no change in social support, e) they involve negotiating barriers, and f) participants who drew from the narrative were generally young and had few responsibilities or commitments at the time of injury. Although life-as-normal stories show and build resilience as well as maintain health and well-being, life-as-normal stories are not without potential issues. These include the possible masking of narrative abeyance and the fact that life-as-normal stories may divert attention away from the ways in which people are oppressed by their environment (which places the responsibility of resilience solely on the individual as opposed to the individual and the environment). Possibilities and problems aside, life-as-normal stories serve as a reminder that SCI does not necessarily have to be storied as life-changing.

## **CHAPTER 9: Conclusions**

### **Overview**

This thesis has uniquely demonstrated what resilience is for people with SCI and how it is fostered. Split into four sections, the first section of this chapter shall begin by discussing the empirical findings of this thesis in relation to resilience for people with SCI. The second and third sections of this chapter shall then discuss the theoretical and methodological implications of this research, before the final section provides a set of practical recommendations for promoting resilience and health and well-being in people with SCI.

### **Part 1: Empirical implications**

#### **What is resilience for people with SCI?**

For almost fifty years scholars have debated the meaning of resilience in their quest to agree on a definition of the concept. This study has suggested, however, that trying to establish a singular, universal definition of resilience is not possible due to the fact that resilience means different things to different people, at different points in time. Across the 19 participants in this study resilience had four different meanings. Accordingly, resilience can be defined in four different ways:

- 1) Endurance of loss following adversity.
- 2) Adaptation to adversity.
- 3) Growth through adversity.
- 4) Living a life-as-normal despite adversity.

Resilience is therefore like a four sided dice in that it is a singular entity possessing four different faces. The next section shall explore how resilience is developed in people with SCI.

#### **How do we develop resilience in people with SCI?**

##### **Dialogical relationships, stories and narrative types**

Following SCI the narrative map (Pollner & Stein, 1996) which participants had once used to navigate through life was no longer useful as it provided no guidance on how to live well with disability. In order to create a new narrative map, participants were required to learn to ‘think differently’ (Frank, 1995, p. 1). In order to do this participant’s needed to tell new stories about

their lives, however, participants could not do this alone due to the premise that ‘we have no internal sovereignty as individuals, we exist only on the boundary with others’ (Frank, 2004, p. 46). Thus, to tell new stories participants had to enter into dialogical relationships with others because ‘stories are always told within dialogues: Storytelling responds to others—whether actually present or imagined—and anticipates future responses, including the retelling of the story, with variations’ (Frank, 2012, p. 33). This gave participants access to certain narrative resources that exist ‘out there’ in society. As such, access to narrative resources was dependent upon participants’ social location (Frank, 2010). In the case of participants this means for example what narrative resources were available where participants lived, or what narrative resources were available in the spinal unit. Following SCI the narrative resources available to participants were in the form of four different narrative types. These were a) the loss narrative, b) the adaptation narrative, c) the growth narrative, and d) the life-as-normal narrative. Participants drew upon these narrative types to tell stories. These stories acted to repair the damage that disability had done to participants’ narrative maps in terms of restoring participants’ sense of who they were as well as where they were going in life (Frank, 1995). It was the repairing of participants’ narrative maps that built resilience. As there were four different types of story that repaired participants’ narrative maps, resilience was therefore built in four different ways. The plot of each narrative type and the characteristics of each type of story formed from each narrative type shall now be summarised along with how each type of story built resilience.

### **The loss narrative**

The loss narrative has the plot: *I lost a lot when I became disabled, I endure this loss*. This narrative type was characterised by stories depicting the dys-appearing body, the loss of mental health, and the loss of social support. Although the loss narrative led to an overall decrease in health and well-being it was an imperative resource from which participants could build resilience. This was because it provided the initial structure from which participants drew to story their experience of SCI, helping them to start to comprehend SCI and begin to rebuild their narrative map. The narrative structure of the loss narrative therefore acted as a life raft to participants, keeping them afloat during times when they may have otherwise sank into *chaos* (Frank, 1995; Smith & Sparkes, 2004). These times included the early stages of SCI as well as subsequent times of need (e.g. during depression). Stories of loss are therefore important as they

may be the only way for people to show resilience in certain situations and remind us that ‘we should not romanticise notions of resilience’ (Lepore & Revenson, 2006, p. 39).

### **The adaptation narrative**

The adaptation narrative has the plot: *Every day I am living better with disability*. This narrative type was characterised by stories depicting control, acceptance, humour, purpose in life, hope for the future, social support, sport, and social comparison. The adaptation narrative worked to restore participants’ health and well-being back to a level of health and well-being that compared to pre-injury as well as providing a resource from which resilience was built. It did this by providing stories that guided participants through formal rehabilitation in the spinal unit, through the transition from the spinal unit into the community, and then through lifelong rehabilitation.

### **The PTG narrative**

The PTG narrative had the storyline: *I have grown from the experience of disability over time*. This narrative type was characterised by stories illustrating health work, strength of character, altruism and empathy, and appreciation. The PTG narrative was important as it enabled participants to transform SCI into an event with a purpose. This built participants’ resilience as well as improved participants’ health and well-being, (sometimes to levels beyond that of pre-injury). Stories of PTG also helped to create a positive disability identity for both individuals and the disabled population.

### **The life-as-normal-narrative**

This narrative had the storyline: *Nothing has changed since I became disabled*. This narrative type led to stories that were characterised by their simplicity, reframing SCI, backgrounding SCI, the continuation of pre SCI activities, unchanged social support, overcoming barriers, and age and life circumstance at the time of injury. These stories built resilience and maintained health and well-being by enabling participants to accommodate their impairment (Gershick & Miller, 1995). In order to do this, participants did not identify with impairment or side-line it either. Instead, in an attempt to make disability not matter, or ontologically unimportant (Watson, 2002) they were able to reconstruct their sense of what was ‘normal’ for them (Watson, 2002). By refusing to be categorised on the basis of bodily difference participants challenged ideas of normality (Watson, 2002). This helps to construct disability as a constantly evolving, unformed,

unfixed concept, ‘reflexively understood by the person in terms of his or her biography’ (Giddens, 1991, p. 53).

### **So what?**

Firstly empirical findings suggest that resilience depends upon others due to the fact that we enter into dialogue and create resilience, or we do not. This is important as it means that resilience is a product of the individual (as the individual seeks the dialogical relationships and narrative resources required for storytelling) as well as the individuals’ family, community and culture (which provide dialogical relationships and the narrative resources required for storytelling).

Secondly, although all four narrative types built resilience, different narrative types had different effects in terms of disability and health and well-being. The growth narrative was most beneficial way of building resilience following SCI as it the most salutary effects on participants’ health and well-being. The adaptation and life-as-normal narratives both work to maintain levels of health and well-being from pre to post injury and therefore can be seen as two different, but equally effective ways of returning to biopsychosocial homeostasis following SCI. Although it must be remembered that the loss narrative may be the only way a person is able to show resilience following SCI (especially during the early stages of rehabilitation), the loss narrative led to a lower level of health and well-being in participants following SCI. As such the loss narrative may be best used as a form of makeshift raft that helps participants survive adversity in the short term, as opposed to the long term. Significantly, this means that it is not resilience per se that affects levels of health and well-being following SCI, but the way in which resilience is constructed. The next section shall now explore the theoretical implications of this thesis.

## **Part 2: Theoretical Implications**

Theoretical implications can be split into three sections concerning a) resilience, b) disability and c) narrative. These shall now be discussed in sequence.

### **What is resilience?**

#### **A process and an outcome**

The decision about whether to describe resilience as a process or outcome has been largely based on the nature of adversity and population being studied (Mancini & Bonanno, 2010).

Developmental researchers (e.g. Luthar, Cicchetti, & Becker, 2000) usually choose to conceptualise resilience as a process, whereas other scholars studying acute trauma (e.g. Bonanno, 2004) conceptualise resilience as an outcome. There are others, however, that conceptualise resilience as a process but measure it as an outcome (Luecken & Gress, 2010). To prevent this from happening it is important to state whether resilience is conceptualised as a process or an outcome.

This thesis builds upon previous resilience literature as it suggests that resilience can be conceptualised as either a process or an outcome. This is because stories and resilience create each other over time. As such, resilience can be viewed as both an outcome (in that it is created by stories), as well as a process in that resilience and stories ‘imitate each other, ceaselessly and seamlessly, but neither enjoys temporal or causal precedence’ (Frank, 2010, p. 21). Concentrating on resilience as a process or an outcome cannot occur simultaneously, however, as whether resilience is seen as a process or an outcome is dependent upon which is in focus at a particular time.

### **Resilience as relational and storied**

As individuals we have no internal sovereignty and we only exist in relation to others (Frank, 2004). In the same vein resilience is not an innate quality that comes from within. Instead it is created by entering into a dialogical relationship with a real or imagined other. Dialogical relationships create the space required for storytelling. It is these stories that create resilience. As such resilience is fundamentally storied and relational.

### **Heterogeneous and homogeneous**

Aligned with Ungar (2008), this study has suggested that resilience is both heterogeneous and homogeneous. Resilience is heterogeneous as it meant different things to different participants at different points in time. For example, at the time of interview two participants understood resilience as the endurance of loss following adversity, thirteen participants understood resilience as adaptation to adversity, two participants understood resilience as PTG from adversity, and the final two participants understood resilience as living a life-as-normal despite adversity.

These understandings were also homogenous however due to the fact that they could be grouped together in these four different ways. As well as this, these understandings shared

similarities with different conceptualisations of resilience from across the literature. Aligned with Ungar (2008) this suggests that some aspects of resilience are homogeneous across populations. The next section shall outline each understanding of resilience and how it relates to the literature on resilience:

- 1) *The endurance of loss following adversity*. Parallels can be drawn between this understanding of resilience and existing conceptualisations such as ‘the ability to successfully cope with change and misfortune’ (Ahern, Kiehl, Sole and Byers, 2006, p. 104).
- 2) *Adaptation to adversity*. This understanding of resilience is concurrent with the vast majority of ways of conceptualising resilience across the literature, for example it aligns with Luthar, Cicchetti and Becker’s (2000) definition of resilience as ‘a dynamic process encompassing positive adaptation within the context of significant adversity’ (p. 1).
- 3) *Growth from adversity*. This growth-related understanding of resilience bears similarities with the definition of resilience used by Ungar (2004) of ‘positive growth and a successful life trajectory’ (p. 349).
- 4) *Leading a life-as-normal despite adversity*. This definition parallels with research by Bonanno (2005) who suggests that resilience is ‘the maintenance of a relative stable trajectory of healthy functioning following exposure to a potential trauma’ (p. 135).

Viewing resilience as homogenous is important as it means that conclusions can be drawn from across the resilience literature in order to inform practice and policy on resilience in both people with SCI and other populations. However, heterogeneity is also salient as it helps us to respect alterity in that we cannot fully ‘know’ what resilience is in other. This is because heterogeneity reminds us that resilience is experienced differently depending upon the context in question.

### **Resilience as contextually situated**

Aligned with research by Cárdenas and López (2010) and Porcelli, Ungar, Liebenberg and Trépanier (2014), this study provides support for the use of the social-ecological model of resilience in people with physical disabilities such as SCI. This was because the model fully accounted for the individual, social, and cultural factors that disabled participants and thus contextually situated resilience in people with SCI. Recognising resilience as contextually



situated is important as it means that a) resilience is a product of the individual and their environment, and b) resilience takes upon different meanings dependent upon the context in question. These points shall now be discussed in order.

Firstly this thesis suggests that resilience is a product of both the person and their environment. For example factors that affected resilience were individual (such as the dys-appearing body and strength of character) and environmental (such as physical barriers and disabling societal attitudes towards disability). Gilligan (2004) explains:

While resilience may previously have been seen as residing in the person as a fixed trait, it is now more usefully considered as a variable quality that derives from a process of repeated interactions between a person and favourable features of the surrounding context in a person's life. The degree of resilience displayed by a person in a certain context may be said to be related to the extent to which that context has elements that nurture this resilience (p. 94)

Understanding resilience as a product of both the individual and their environment is important as individualistic accounts of how disabled people 'beat the odds' (Seccombe, 2002, p. 384) in order to show resilience have often been unhelpful. This is because individualistic accounts a) blame the individual when resilience is not shown and b) do not take into account factors such as how people with disabilities are oppressed by disabling attitudes in society and physical barriers. Focusing upon both individual and environmental factors means that emphasis can be placed upon 'changing the odds'. For example, rather than encouraging individuals to overcome environmental barriers we should concentrate on removing environmental barriers (where possible). This is in step with attempts to make psychology less an individualistic encounter and more a community intervention (Runswick-Cole & Goodley, 2013).

Secondly, by suggesting four different ways of constructing resilience following SCI this research concurs with recent cross cultural research by Ungar and colleagues (e.g. 2007, 2008, 2011) suggesting that resilience takes upon different meanings dependent upon the context in question. This means that resilience cannot be defined in a singular, universal way not only across different populations, but also within different populations. This is important as it suggests that different ways of operationalising and defining resilience can not only sit

comfortably with each other, but also complement each other as alternate ways of constructing the same phenomenon.

This study is unique in that it is the first study on resilience in people with SCI to have shown sensitivity to the community and cultural factors that contextualise how resilience is defined and manifested in everyday practices. The main example of this is the influence of the four resilience narrative types (loss, adaptation, PTG and life-as-normal) on participants' resilience following SCI. These narrative types exist 'out there' in society and therefore account for the influence of community and culture on resilience in people with SCI. This is important as resilience research has traditionally concentrated upon the importance of the individual and their relationships with family and friends when trying to understand resilience at the expense of the community and cultural factors (Ungar, 2004, 2005, 2008; Boyden & Mann, 2005).

Taking into account the influence of community was important as it highlighted that many participants spent most of their time immersed in the SCI community (and the wider disability community) rather than in, for example, the local community where they live. This suggests that participants were either being drawn towards the disability community, or away from the local community. People with SCI may be drawn towards the disability community because they can participate in sport which is adapted to their disability, or that they can learn more about how to live with SCI from their peers. However, people may also be pushed towards the disability community if they feel excluded from their local community. People may also be pushed away from their local community due to physical barriers, for example when Chester talked about having to push his chair through the mud on the way to his local shop because cars were parked on the pavement (see page 57). More needs to be done to help people with SCI integrate into the local community as well as the disability community. This is because the local community also has resources that can foster resilience in people following SCI and is often more closely located to the individual than the disability community.

Viewing resilience as contextually situated is also important in the spinal cord injured population as examples of hidden resilience can be identified. For example, this study has identified that for some participants the only way of showing resilience was through the endurance of loss. This goes against previous research (e.g. White, Driver & Warren, 2008) which suggests that features of the loss narrative (such as depression) imply vulnerability as

opposed to resilience. Care must be taken against taking pre-existing conceptualisations of resilience (which have often been formed in white, western, able bodied populations) and using them as a benchmark to decide what constitutes resilience and what does not across different cultures and contexts.

### **Resilience and sport**

Aligned with Stewart and Yuen (2011), playing sport was associated with increased resilience following SCI, as well as the maintenance of health and well-being. This was for two main reasons. The first reason was that participants could build an affirmative disability identity (Swain & French, 2000) through playing sport. As such it was important to introduce participants to adapted sports (such as wheelchair rugby and wheelchair tennis) as quickly as possible following SCI. The spinal unit was therefore ideally positioned to introduce participants to sport during the process of formal rehabilitation. Following rehabilitation participants sought out local clubs in which they could play organised sport.

Secondly, sport was also an area in which served to challenge both disabled and able bodied people's perceptions of physical impairment. This was especially so when disabled sports were given positive media attention. For example, high profile events such as the Paralympics are especially important as they go some way towards placing disability sport on a level playing field with able-bodied sport, increasing its value, visibility and media coverage. However, it must be remembered that as well as having the power to challenge the meaning of disability in society, stories of sport and the disabled athlete can also oppress disabled people (Shapiro, 1993). This occurs when the disabled athlete is portrayed as a supercrip (see below page 133). Care must be taken to promote stories of the disabled athlete as opposed to the supercrip when developing resilience through sport following SCI.

### **Disability**

This research is important as it links the concept of resilience to people with disabilities, illuminating numerous examples of how participants overcome great adversity in order to achieve health and well-being. This is salient as the disabled population are not always a population perceived as showing resilience. The following section shall explore disability and resilience from a social-relational perspective.

## **A social-relational approach to disability**

The social model of disability is of great importance to disabled people as instead of focusing on disability as an individual deficit, it concentrates on the ways in which disabled people are oppressed by the environment. However, the social model is not without limitations (examples include the division of disability and impairment, impairment is reduced to biological, the body is denied, lived experience is denied, and it essentialises people with disability). A social-relational approach (Thomas, 1999, 2004) to disability overcomes these limitations by recognising impairment, its physical restrictions, and its psychological dimensions. This approach encompasses oppression at both micro and macro level, in the relationships between disabled and able bodied people (Thomas, 2004). In line with Thomas (1999), this understanding of disability provides a firm foundation for an enriched view of disability. This was for the following reasons.

Firstly, the social-relational approach enables the exploration of psycho-emotional dimensions of disability in relation to resilience. This was important as it enabled loss of self-esteem and feelings of inferiority to be seen as instances of psycho-emotional disablism as opposed to an individual deficit:

Medical approaches consider negative self identity to be an outcome of physical impairment, and focus on the need for adjustment, mourning, and coming to terms with loss. Social approaches view negative self-identity as a result of the experience of oppressive social relations, and focus attention on the possibilities for changing society, empowering disabled people, and promoting a different self-understanding (Shakespeare, 1996, p. 99)

Accounting for loss of self-esteem in this way was important as it helped to illuminate that participants were actually enduring psycho-emotional disablism in order to show resilience. Effectively this means that people who show resilience following SCI are often those who can endure psycho-emotional disablism. This is problematic as in this situation resilience isn't benefitting participants' health and well-being and instead it is obscuring a loss of health and well-being. As such, we firstly need to be aware that resilience can obscure disablism, and secondly, we need to focus upon reducing psycho-emotional disablism so that people with SCI

can live in environments that enhance resilience as opposed to environments that demand resilience.

Secondly, by taking into account the lived experience of disability (via impairment effects and psycho-emotional dimensions of disability) the social-relational model enables us to *claim loss* (Watermeyer, 2009). This is in line with medical approaches towards the study of disability (which theorise about, or at least imply the psychological experience of loss following disability) (e.g. Solnit and Stark 1961; Vash & Crewe 2004; Siller 1969, cited in Watermeyer, 2009), and in contrast to social model perspectives towards the study of disability (which argue that the concept of loss implies that the disabled person is vulnerable, or incomplete) (e.g. Abberley 1993; Oliver 1990; Finkelstein and French 1993; Morris 1989; Lonsdale 1990; Watermeyer 2002). Claiming loss in this manner is important as it enables us to recognise and validate the very real experience of loss in people with SCI whilst also accounting for its socially constructed nature. Viewed in this way, the experience of loss does not have to imply vulnerability; instead it can be seen as a ‘ubiquitous, even essential, aspect of the human condition’, associated with growth and development’ (Watermeyer, 2009).

Thirdly, the social-relational approach enabled the exploration of resilience as an embodied practice following SCI by taking into account impairment effects. This was important as participants’ resilience was created by the stories they told about their impaired bodies. For example stories of loss, adaptation, growth or life-as-normal gave impairment meaning and this meaning influenced resilience and health and well-being. The body was also important as it affected the stories participants could or could not tell. For example impairment effects (such as reduced movement and mobility, reduced control of bodily function and pain) often led to stories of loss as opposed to stories of PTG. Although stories of loss had a negative influence on health and well-being, this was sometimes the only way of constructing resilience due to the constraints of the body. For these reasons a social-relational approach is therefore important to the study of resilience in people with SCI as resilience is an embodied practice.

Finally, the social-relational model enables the exploration of how people are constrained not only by their body, but also by other people. For example, other people may force the disabled person into telling a certain type of story. As Frank (2013) noted:

The risk of the life-as-normal narrative is that the people around the person are choosing to treat their lives as normal (or abnormal), and the disabled person is subtly (or not) coerced into accommodating their anxieties (p. 196)

This is because others determine what is *narratable* and what is not (Bérubé, 1996; Frank, 2004). For example social conventions may shut down story-telling about loss, forcing the disabled person to tell life-as-normal stories. This may mean that it may only the minority who have ‘truly chosen’ to live by a life-as-normal story (p. 197). This is problematic as there costs to telling (or not telling) certain kinds of stories in terms of resilience and health and well-being.

### **The supercrip**

Traditional approaches assume that to show resilience a disabled person must become a supercrip (Runswick-Cole & Goodley, 2013). Supercrips are ‘those individuals whose inspirational stories of courage, dedication, and hard work prove that it can be done, that one can defy the odds and accomplish the impossible’ (Berger, 2008, p. 648). Rather than being extraordinary, however, this thesis found resilience to be very common with all nineteen participants showing resilience following SCI. This is significant as it means that either a) all participants had to become supercrips in order to show resilience or b) there are different ways of showing resilience other than becoming a supercrip This section shall explore these two ideas.

First and foremost resilience is a product of both the environment and the individual. However, as was suggested in the previous section, participants were very often disabled by the built environment and by others around them as opposed to their physical injury. As such the environment was generally not resilience enhancing and instead it can be seen as resilience demanding. The demands such environments placed upon individuals are rarely seen by people who aren’t disabled as participants’ resilience obscures the lived experience of disability. As such we don’t tend to hear stories of how people accomplish the seemingly impossible on a day to day basis following SCI. Due to this it can be argued that every participant had to effectively become a supercrip in order to show resilience following SCI.

The second explanation is that all participants cannot be supercrips as to be a supercrip implies defying the odds. This would suggest that there are many other ways of showing resilience rather than becoming a supercrip (such as through stories of loss, adaptation, growth or life-as-normal). These ways of showing resilience may be more beneficial for people with

disabilities as the supercrip is problematic for a number of reasons which are as follows. When the media depicts elite sporting athletes as supercrips (or when athletes with disabilities themselves operate as or seek to be a supercrip), this supports the low societal expectations of disabled people, reproducing a tragic image of disability, perpetuate heroic and hegemonic notions of masculinity and 'reinforce social systems of domination, equating individuals' self-worth with coming out on top in the competitive struggle for achievement' (Berger, 2009, p. 131). The supercrip athlete in the media, or in the community talk may likewise be disempowering because what is generated, it might be argued, is a de-politicised, pre-social and false impression that all is needed when one is impaired is heroic individual effort and inner drive to overcome societal barriers (Berger 2009; Hardin and Hardin 2004; Kleiber and Hutchinson 1999). In other words, the types of reform advocated by proponents of the social model are unnecessary because individuals by themselves can, and should, heroically rise to the challenge of overcoming barriers. Thus, it might be said, there are problems with supercrip athletes and how they are depicted not just in the media, but in everyday life too.

Importantly both explanations lead to the same conclusions. Rather than concentrating on building an individual's resilience following SCI we firstly need to highlight the ways in which people's resilience is hidden by oppressive environments. Secondly, we need to try and eliminate oppression so that the environment fosters resilience rather than demands resilience. Thirdly, we should not encourage the notion of the supercrip as the supercrip encourages unrealistic expectations about what people with disabilities can, and should be able to achieve, if only they tried hard enough (Berger, 2008).

## **Narrative**

Traditional models of adjustment suggest that people pass through predictable stages following the experience of loss (e.g. Charmaz, 1994, 1995; Gill, 1997; Salick and Auerbach, 2006). This is problematic for a number of reasons. Firstly it generalises the unique experience of disability. As Frank (1991) notes:

Panic is mine entirely, not some "stage." The last thing an ill person needs is to be treated as "only going through a panic stage." The individuals panic may be mitigated because it is shared, but it cannot be dismissed because it is expected.

Knowing that panic is normal does not resolve the feelings evoked in panic (pp. 46-47)

By generalising an individuals' experience stage theories fall short as they fail to care for the disabled person. This is because they only recognise the similarities between individuals. Instead, as Frank (1991) notes it is 'only by recognising the differences in our experiences can we begin to care for each other' (p. 42). Stories account for these differences by recognising and attending to participants' unique experience of SCI. As such, stories are important as they care for people with SCI throughout their lives.

The second reason stories of SCI are important is because 'life experiences overlap' (Frank, 1991, p. 42). As such, stage theories do not do justice to the empirical world that has been observed. Although the structure of this thesis creates the 'illusion of order' (Frank, 1991, p. 42), the disability experience does not necessarily progress sequentially. Participants showed resilience following SCI by telling different kinds of stories (i.e. loss, adaptation, PTG and life-as-normal) alternatively and repeatedly (Frank, 1995). The boundaries between these stories are permeable enabling stories to change shape and merge with other stories. As such it is very difficult to know when one story ends and another begins as stories distort the clear cut distinction. For example two stories, such as adaptation and PTG, or loss and PTG can run side by side, or one in front of the other, constantly moving around. Aligned with Day (2013), this is important as it illustrates that PTG can occur alongside loss. Representing the empirical world as a set of stories is therefore useful as enables the complexity of resilience following SCI to be accounted for.

Thirdly, stage theories foreclose alternate ways of living with disability and therefore risk finalising (Bakhtin, 1984) the participant. Finalisation occurs when an author claims to have the last word about who another person is and who they can become. This prevents people from growing and changing as the researchers account becomes the character's fate. Stories are important as they enable people to evolve and change over time as well as to imagine alternate ways of living with disability.



### **Part 3: Practical implications**

A number of practical implications for fostering resilience in people with SCI have arisen from this thesis. These are telling stories, resisting dominant narratives, and identifying narrative environments that enhance resilience. Each shall now be explored in turn.

#### **Telling Stories**

Stories ‘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’ (Smith, 2013a, p. 110). Stories affect ‘what people are able to see as real, as possible, and as worth doing or best avoided’ (Frank, 2010, p. 3). This means that the stories an individual tells can change themselves and others around them. This has a number of implications.

The main practical implication of this research was that telling of resilience stories (i.e. loss, adaptation, PTG and life-as-normal) acted to repair the damage that disability had done to participants’ narrative maps in terms of restoring participants’ sense of who they were as well as where they were going in life (Frank, 1995). It was the repairing of participants’ narrative maps that built resilience. As such following SCI people should be encouraged to enter into dialogical relationships with others in order to allow them to tell stories of resilience.

Secondly, although all four types of story built resilience, stories had differing effects on participants’ health and well-being and were therefore useful at different times. For example, stories of growth had the greatest salutary effects and therefore should be encouraged as the most health-enhancing way of storying resilience following SCI. These stories were only developed in hindsight, however, and therefore participants were not able to tell stories of growth immediately following SCI. Stories of adaptation worked to restore health and well-being and were therefore especially important during rehabilitation in the spinal unit and on return to the community. Life-as-normal stories were also useful as they work to maintain health and well-being. Not everyone may be able to tell life-as-normal stories however, for example if they had experienced significant change in their lives following SCI. Although stories of loss had an overall negative effect on participants’ health and well-being they were imperative as they helped participants’ endure the experience of loss. This prevented participants’ health and well-being from falling any lower during really difficult times, for example in the early stages following injury. Different stories of resilience are therefore useful at different times and for different purposes following

SCI. This means that certain narrative types cannot be seen as inherently ‘good’ or ‘bad’, or ‘better’ or ‘worse’ than other types of narrative as each narrative type has its specific role in building resilience following SCI.

Thirdly, as participants told and retold their resilience stories it enabled them to be heard by themselves and by others. This helped to educate others (for example family, the general public, and health care professionals) as well as educate spinal cord injured people themselves. Stories of loss were particularly important as they illuminated the ways in which participants were restricted by their bodies as well as oppressed by the social environment. This can help challenge physical barriers, psycho-emotional disablism and the normative cultural assumptions our society holds about the human body and how it should behave. This helps to reduce or eliminate the oppression of disabled people by society.

Fourthly, it was also important for participants to hear stories that resonated with their own experiences of SCI as these stories enabled participants to feel understood as well as reminding them that they weren’t alone (Kilty, 2000).

Finally, telling stories provides counter narratives that help people imagine alternate ways of living with SCI. The more alternate narratives there are to choose from, the more likely it is that a person can find a narrative that helps them show resilience. For example, *naming pain* (Sparkes & Smith, 2008) helped participants to show resilience as it created more narrative resources from which participants could draw in order to express their pain. Although expression did not reduce the visceral feeling of pain, it enabled participants to share their pain. The sharing of pain made the experiencing pain more endurable, building resilience following SCI.

### **Listening devices**

This thesis has named four different types of narratives that participants use following SCI. These were the loss narrative, the adaptation narrative, the PTG narrative and the life-as-normal narrative. But why propose different types of narrative? The advantage of proposing different types of narrative is that they act as *listening devices* (Frank, 1995):

*Listening devices...* encourage closer attention to the stories ill (or disabled) persons tell; ultimately, to aid listening to the ill. Listening is difficult because illness stories mix and

weave different narrative threads. The rationale for proposing some general types of narrative is to sort out those threads (p. 76, brackets added).

Narrative types also work by encouraging people to reflect upon what story they have been telling, or not telling, and how this story is helping or hindering them (Smith & Sparkes, 2008; Frank, 2012) and others they care about (White & Epston, 1990). This allows people to label and externalise their narrative orientation as something outside of the self.

Finally, naming narratives ‘can authorise the telling of particular stories, and it can also liberate people from telling stories they no longer want to tell’ (Frank, 2010, p. 119). People with SCI may then be more able to ‘recognise and reinforce actions and attitudes that challenge the hegemony of a problem-saturated story of their identity’ (Neimeyer, 2004, p. 58). For example following SCI people can recognise if they are telling a story of loss and begin to tell a story of PTG.

### **Narrative environments that enhance resilience**

Narrative environments are very important in the creation of resilience. For example, the spinal unit is very important in creating resilience as it gives people hope for the future via a goal setting process. It achieves this through a structured program which includes both the maximisation of physical function, and the instilling of a set of ideas and philosophies (Ory & Williams, 1989). Through these ideas and philosophies, tailored to each individual’s needs, the rehabilitation team direct, prompt and script the process of rehabilitation (Mattingly, 1998a), teaching a new bodily habitus (Bourdieu, 1977) or way of being in the world (Merleau-Ponty, 1962). Forming a story by emplotting the goals of rehabilitation is one way of doing this (Mattingly 1994, 1998a, 1998b), providing an outline and a timeframe (Gubrium, Rittman, Williams, Young & Boylstein, 2003) for the restoration of ‘normality’ following SCI. This means that through the use of medical benchmarks, the spinal unit is an ideal place to promote narratives that promote progression. In this way, benchmarks become the foundation of adaptation narratives (Warren & Manderson, 2008) and promote hope, acting to help people with SCI practice health work. Both the spinally injured person and practitioners should focus on building a goal attaining environment, as well as exploring the pathways by which these goals can be attained (Barnum et al, 1998) in order to promote resilience, and health and well-being.

## Part 4: Methodological Implications

There were three methodological implications arising from this research for the field of qualitative research. These were the usefulness of dialogical narrative analysis (DNA) (Frank, 2010, 2012) as a form of analysis, timelining as a form of data collection, and the use of dictation software to aid with the process of transcription.

### Dialogical narrative analysis

We know how DNA works theoretically but as yet we still know very little about how DNA works empirically. This is because DNA is a relatively new form of analysis and therefore has only been used in a small number of studies (e.g. Blix, Hamran, & Normann, 2013; Caddick, 2014; Smith, 2013b). This section will provide an insight into how DNA can help us explore the areas of resilience, disability, and narrative.

Viewing stories as *material semiotic companions* (Frank, 2010, p. 42) or ‘actors’ enabled the exploration of how stories shape peoples’ experiences of resilience and health and well-being. Stories began by making the earth habitual for people following SCI by providing a guidance system. For example, stories of loss were of particular importance in the initial stages following SCI as they enabled participants to make sense of the ‘blooming, buzzing confusion’ (James, 1981, p. 462) that they had been cast into. This built participants’ resilience and prevented participants’ health and well-being from falling any lower. However, although this means that in one way the loss story cared for participants following SCI, in another way stories of loss were dangerous as they often meant that participants endured psycho-emotional disablism as opposed to challenging psycho-emotional disablism. Furthermore, they also meant that participants’ performed emotional work so that they did not lose social support. Although emotional work built resilience, the trouble arises when the disabled person ‘may not feel like acting good-humoured or positive’ as ‘much of the time it takes hard work to hold this appearance in place’ (Frank, 1991, pp. 65-66). Thus, there can be dangerous consequences of such emotional work in that sustaining a cheerful image costs energy. More worryingly, however, it also costs opportunities to express what is happening in a spinal cord injured person’s life so that, the spinally injured person’s life can be understood (Frank, 1991). For Frank (1991), attempting a positive image in front of others diminishes relationships with others by preventing them from sharing in the injury experience. As such, the loss story can cure, but it

also can injure (Frank, 2010). In order to increase the rate of cure and reduce the rate of injury we need to look towards alternate stories such as stories of adaptation, PTG and life-as-normal. For example, the adaptation and life-as-normal narratives work better at maintaining participants' health and well-being. To summarise, DNA was very important to the study of resilience in people with SCI as it was only once we recognise what a story is doing to a participants' resilience and health and well-being, then we can begin to kindle their resilience and health and well-being via the promotion of certain types of story over others.

### **Timelining**

Timelining was used to plot participants' health and well-being over the course of their life. As well as stimulating the participants' memory, timelining also helped participants' to articulate their storied experience of resilience over time, whilst highlighting important turning points in their lives. Although timelines were unique to each individual, when grouped together a set of commonalities became apparent. From these commonalities we can glean an understanding of the relationship between resilience and health and well-being following SCI.

The timeline was useful throughout the interview process as it allowed movement forwards and backwards in a non-linear manner rather than the participant trying to tell their story through from start to finish. This non-linearity also allowed participants to break their life history down into more manageable events, concentrating on each time in their life in more detail and as such constructing a more in depth and complex narrative. This was concurrent with work by Sheridan et al., (2011) who suggested that this form of graphic elicitation has particular value for narrative forms of research as it encourages the construction of rich temporal narratives.

Secondly, timelining helped the participant to recall all of the main events in their lives over time. Thinking about their lives from their earliest memories to the current moment and plotting them on a graph appeared to stimulate their memory. The timeline allowed them to go back and forward in time, adding things that they had forgotten about, or were less important. This enables participants to think about their timeline in greater depth, enabling them to contemplate how their lives have changed over time. The timelining was also useful visually. Plotting the different points allowed the participants to compare the different times in their lives and then illustrate to me how these times compared to each other. The graphical representation provided a rough pattern of the participant's experience over time. The ups and downs each

participant experienced were often quite dramatic, but there were also times of gentle decline or incline. This clearly illuminated any major transitions which I could then question further to try to understand why the transition had occurred.

I tried using the timelining technique at different points during the interview. In the first two interviews I used it to get the interview started. This was useful as the participant and I could return back to it throughout the whole interview, however, having it at the start of the interview felt like a difficult, slightly awkward, and unnatural way to begin. After the second interview I began using timelining once the unstructured part of the interview was coming to a close. This provided a nice break before conversation was re-invigorated for the second part of the interview. This technique became slightly problematic when initial conversation went on for an extended period of time, however. It felt unnatural to bring in the timeline without a break in conversation. This led to the timeline being completed very near to the end of the interview on one occasion which meant that we didn't have time to use the timeline to refer back to during the interview.

Timelining can be problematic in people with SCI depending on the person's level of injury. For example because Mitch had no movement in his arms he had to describe to me where to plot his high and low points on the axis. This was problematic as I couldn't be sure of exactly where to plot each point. In this instance timelining therefore only provided an approximation of health and well-being. On another occasion I didn't use timelining in the initial interview as it didn't feel appropriate. This was because Margaret did the interview from her bed so it would have been difficult for her to plot the points for herself, or direct me to plot the points for her as she would not have been able to see the piece of paper properly. Another difficulty was that participants often found it hard to place different events on the health and well-being axis. This was because it was challenging for them to compare different highs and lows. For example, how does SCI compare with divorce in terms of its effect on health and well-being, and how does childhood compare to adulthood in terms of happiness?

### **Dictation software**

Voice recognition software was used to transcribe participants' interviews. This benefitted the research process in a number of ways. Firstly, using dictation software saves a vast amount of time; transcription took between two and three hours per hour of recording instead of taking

between six and eight hours when typing. This time frame includes the time spent dictating and making corrections. Dictation takes approximately one hour and thirty minutes per hour of interview depending on the pace at which the participant speaks. Corrections then take approximately another hour, per hour of interview depending on the number of errors. The number of errors when dictating depends substantially on how carefully you choose to dictate. Many errors can be eliminated by spending extra time pronouncing words clearly. If the interviewee has a strong accent this can sometimes affect the accuracy, as when repeating their words it is easy to mimic the participant's pronunciation.

Whilst using voice dictation software I could dictate for much longer periods of time than I would usually be able to type. I found talking to be much less tiring than typing and improved the length of time I could concentrate for. As well as this, heightened levels of concentration also allowed me to listen more attentively and engage with the material more thoroughly. Dictation also allowed my hands to be free to take notes.

There were also a number of drawbacks to the use of dictation software, however. For example, sometimes the dictation software cannot keep up with the speed of dictation. When this occurs there is the option to stop and wait for the software to catch up, or the option to just carry on and the software will catch up at the end. However, this can be problematic as errors can easily occur. For example, the dictation software can also be used to control your computer using your voice. Occasionally the software misrecognises your words as a command to begin dictating into another program or document rather than onto the transcript. This can result in having to stop the software and losing the words you have just dictated. In addition to this, using dictation software requires talking out loud and therefore if the interview is confidential you will have to work alone as opposed to in an environment with others.

### **Concluding thoughts and future possibilities**

This thesis has illustrated the capacity of stories to *do* things. Following SCI four different types of story (loss, adaptation, PTG and life-as-normal) acted as guides through the 'blooming, buzzing confusion' (James, 1981, p. 462). Taking four different routes, these stories built resilience along the way. Stories of loss built resilience by enabling participants to begin to grapple with SCI and 'survive' (Ahern et al., 2006). Stories of adaptation accompanied participants through the rehabilitation period, and on return to the community, helping them

learn to live with disability. Stories of PTG were told in hindsight and enabled participants to appreciate their lives and what they had gained from their experience. Life-as-normal stories enabled participants to live their life as they had done prior to injury by placing disability in the background as much as possible, for as long as possible. This thesis has two main take-away points. The first point is that resilience is storied and contextual. This meant that resilience took upon a different meaning dependent upon the story being told. The second main take-away point is that stories did not just appear from anywhere. This meant that resilience was relational in that resilience was created in the space provided by dialogical relationships.

This research only examined the lives of 19 people with SCI. Future studies could build upon this research by listening to the stories of more spinal cord injured people. Other stories may build resilience in different ways and as such more narrative types could and should be identified. The more stories people have to choose from, then the more likely it is that they will be able to find a story which acts as a good companion to them through SCI. It would also be interesting to find more people telling life-as-normal stories in order to explore this narrative type further, as only two participants used this narrative type to build resilience.

Another area of future investigation could be to explore the social-ecological model more thoroughly. For example, this study has only listened to spinal cord injured peoples' stories. Although these stories have enabled the investigation of how resources 'out there' in society influence resilience, it would be useful to collect stories from families, communities (such as the spinal unit or local community), and from different cultures to paint a more detailed picture of how different stories are circulating at different levels of the model.

Alternative methods of data collection could also be used to add layers of complexity to participants' stories. The use of visual methods and/or photo elicitation may provide different insights, for example it could help participants talk about things that they found difficult to talk about during an interview. Moreover, the use of audio diaries could provide data on the day to day construction of resilience through stories. We could learn more about when certain stories are told temporally and how different stories relate to each other over time.

This thesis has answered questions such as what is resilience in people with SCI, how is resilience fostered, and how can we use resilience to develop health and well-being. Moreover, this research has roused yet more avenues for future inquiry. My hope is that by sharing these



peoples' stories of SCI this research will help people with SCI reflect upon the stories that they tell, and what these stories are doing in terms of their resilience and health and well-being. As well as this, my hope is that stories can educate people about SCI so that families, communities and cultures can be better able to provide resilience enhancing environments for people with SCI.

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## APPENDICIES

### Appendix A – Recruitment letter



Dear Sir/Madam

As a member of [for example, Spinal Injuries Association], we are hoping that you will consider helping us with a research project we are conducting on resilience and wellbeing in the face of spinal cord injury. The research is led by Miss Joanna Kirkby (Loughborough University). We are very interested in exploring experiences of resilience among both spinal cord injured persons and their family. This would involve 2 separate interviews per person arranged at a time and place convenient to you. No family members will have access to what you say in the interviews. In the interview we would like you to tell us, in your own way and at your own pace, about your experiences of resilience in the face of spinal cord injury. There are no 'right' or 'wrong' answers. It is your experiences, and what you want to tell us about them that we wish to hear. We expect each interview to last 1 hour. In addition, we would like you to take some photographs about your everyday experiences of resilience. We would also like you to keep a diary for about 5 minutes per day over 2 weeks on a digital recorder we provide. We hope that that the findings will assist in developing awareness and knowledge regarding how best to support quality of life and well-being for both spinal injured adults and their families.

With your permission, the interview will be tape-recorded and then transcribed for analysis. The audio diary will also be transcribed. No one beyond the research team will have access to the contents of the interview, diary, or photographs. This oral data will remain confidential. For example, real names will not be used and place names will be changed. We will also ask you if we can use the photographs you take throughout the whole project. The use of personal data conforms to the University data protection guidelines and will be anonymised throughout the process. Should you wish, we would be very happy to share the results of our study with you and discuss our findings?

Due to the aims of the research we are interested in speaking with individuals who are spinal injured and 2 of close family members (e.g. wife and father). We are seeking then to speak with 3 people from the family: 1 who is spinal injured and 2 close relatives of the injured adult. All people must be 18 years of age or above and living in the community (i.e. not still a patient in a spinal injury unit).

Should you willing to be interviewed, or wish to discuss the project further, then please contact Dr Brett Smith by e-mail [B.M.Smith@lboro.ac.uk] or telephone [01509 226367].

Yours sincerely,

Miss Joanna Kirkby

## **Appendix B – Participant information sheet**



### **Understanding resilience, health and wellbeing among spinal injured adults and their families**

#### **Participant Information Sheet**

##### **Chief investigator**

Name: Joanna Kirkby

Address: School of Sport, Exercise & Health Sciences, Loughborough University, Loughborough, LE11 3TU.

Email address: [J.kirkby2@lboro.ac.uk](mailto:J.kirkby2@lboro.ac.uk)

##### **What is the purpose of the study?**

Why, after a spinal cord, do some individuals and families adapt more successfully than others when they leave rehabilitation and move back into the community? The answer might involve resilience. Individuals and families who positively adapt to a traumatic event are often described as resilient. Yet, very little is known about resilience in the lives of either spinal injured adults living in the community or their families. Without this knowledge, it is very difficult to develop and advocate guidelines and interventions for promoting resilience. The purpose of the study, then, is to explore resilience, health, and wellbeing among disabled adults and their families.

##### **Who is doing this research?**

Miss Joanna Kirkby (Loughborough University) is a researcher who conducts the interviews.

##### **Once I take part, can I change my mind?**

Yes! After you have read this information and asked any questions you may have we will ask you to complete an Informed Consent Form, however if at any time, before, during or after the sessions you wish to withdraw from the study please just contact the main investigator. You can withdraw at any time, for any reason and you will not be asked to explain your reasons for withdrawing.

##### **How long will it take?**

You will be invited to take part in 2 interviews. Each interview is expected to last 1 hour. You will also be invited to keep an audio diary for 2 weeks. It is expected this will take about 5 minutes per day. You will also be invited to take photos and keep an audio diary during the study period.

##### **What personal information will be required from me?**

During the interview, when keeping an audio diary, and doing the photography task, you will be asked a series of questions that focus on:

(a) your experiences of spinal cord injury

- (b) your perspectives on resilience in the face of spinal cord injury
- (c) the impact of spinal cord injury on your general health and well-being
- (d) the factors you think that helped or constrained your well-being

### **Are there any risks in participating?**

Due to the nature of interviewing the purpose of the study, there is the possibility that you may experience some distress. If you do please note that at any time you do not have to answer any question and you can command the tape recording to be stopped. You may also terminate the interview when you wish. If you do experience distress, a number of professional support networks that, if you so wish, and without any questioning from the researcher, are available. If you also feel distress relative to your audio diary these professional support networks that, if you so wish, and without any questioning from the researcher, are also available. You do not have to take photographs or give audio diary entries each day if you so wish and can stop at any time without any questioning from the researcher.

### **Will my taking part in this study be kept confidential?**

The use of personal data in Loughborough University conforms to data protection guidelines and all effort will be taken to maintain your confidentiality throughout the research. For example, the interviews will be tape-recorded and transcribed. Your real name will not though be used in these transcripts or thereafter in any public document or talk. Places (e.g. where you live), names of family members, doctors, psychologists, nurses, and other health professionals you may talk about will also be changed. All data will be transcribed into a pass-worded protected computer. Recordings and transcripts will be kept in a locked cabinet in Loughborough University. Only the people involved in the project will have access to the information. The photographs you produce will be returned to you on every occasion we use them. We will never use them if you do not want us to. All faces will be covered with a large black stripe so other people cannot identify faces. All information, including tapes, photographs, and transcripts, will be destroyed within three years of the completion of the investigation.

### **What will happen to the results of the study?**

The results of the study will be published in public documents. These include professional journal articles and spinal injury magazines. The results will also be used in presentations. It is hoped the results will improve both spinal cord injured people's and their families psychological well-being.

### **I have some more questions who should I contact?**

Miss Joanna Kirkby

### **What if I am not happy with how the research was conducted?**

*The University has a policy relating to Research Misconduct and Whistle Blowing which is available online at [http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing\(2\).htm](http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing(2).htm). Please ensure that this link is included on the Participant Information Sheet.*



## Appendix C – Informed consent form



Understanding resilience, health and wellbeing among spinal injured adults and their families

### **INFORMED CONSENT FORM** **(To be completed after Participant Information Sheet has been read)**

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethical Advisory Committee.

I have read and understood the information sheet and this consent form.

I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in the study.

I understand that I have the right to withdraw from this study at any stage for any reason, and that I will not be required to explain my reasons for withdrawing.

**I understand that all the information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others.**

I agree to participate in this study.

Your name

---

Your signature

---

Signature of investigator

---

Date

---

## **Appendix D – Interview guide**

### ***‘Grand tour questions’***

Tell me something about your life?

1. Tell me about your lifestyle before the injury happened.

### **Resilience profile (pre injury)**

2. How resilient were you before the spinal cord injury happened?
3. What did resiliency mean to you then?
4. How did you develop resilience?  
Probe: quality of life, well-being, social
5. Where do you get your resilience from?
6. What stopped you being resilient then?

### **Resilience profile (post injury)**

7. How resilient are you now?
8. What does resiliency mean to you now?
9. How have you developed resilience?  
Probe: quality of life, well-being, social
10. What stops you being resilient?
11. Where do you get your resilience from?
12. How does resilience impact on your health
13. How does resilience impact on your wellbeing / happiness
14. Do you think resilience learnt? If so, how...
15. How could your resilience be improved?
16. How could your family's resilience be enhanced?
17. If you met someone before they became injured, what advice would you give them?

### **Closing**

18. Is there anything else that you would like to tell me about your experiences?

## Appendix E – Interview Prompts

### Resilience

#### 7 Tensions

Access to material resources

How do you afford to live?

Do you work?

Do you receive any financial support? Is this enough?

What does this allow you to do?

What is your level of education?

Do you have the opportunity to be educated further?

#### Cohesion

Do you feel part of your family? If so how are you involved?

Do you feel part of a larger community? If so how are you involved?

What does it mean to you to be part of your family?

What does it mean to you to be part of your community?

Do you feel part of anything larger than your own life?

#### Social Justice

Do you feel that you have a role in the community?

Do you feel that your voice is heard?

Do you feel equal to others in society?

#### Power and Control

How do you care for yourself?

How do you care for others?

Can you change your own environment?

How would you/ have you done this?

#### Identity

How would you define yourself?

How do others see you?

How do you like to be seen?

Do you have a sense of purpose in life?

What do you feel are your main strengths and weaknesses?

What are your aspirations for the future?

What were your aspirations before you became injured?

How did injury change these aspirations?

How did you change as a person when you became injured?

How has injury affected how you define yourself?

How has injury affected how others see you?

What has having to change your identity been like?

How would you describe your philosophy/outlook on life?

What kind of things do you look forward to in life?

What kind of things do you not look forward to?

What kind of things do you do to cope with your injury?

What affects the way you cope with your injury?

Are there any times when you don't feel very good about life, if so when?  
How have these changed compared to before you were injured?  
What do you feel about the time prior to your injury?  
How do you cope when you feel like this?  
How did you cope with rehabilitation?  
How did you cope with going from rehabilitation into the community?  
How do you find living in the community now?  
How does this compare to before you were injured?

#### Relationships

Who is your main caregiver?  
What is your relationship like with them?  
How does your injury affect them?  
How do you feel about them?  
Do you feel that you give anything back to them?  
How would you describe their resilience?  
Who do you have close relationships with in your life?  
How often do you see these people?  
How do they help you?  
How have these relationships influenced you?  
What is the most important thing about these relationships?  
What do you do when you see your friends and family?  
What is your relationship like with the larger community?  
How are you treated by those close to you?  
How are you treated by the wider community?  
If you needed support who could you rely upon?  
How do you feel about asking for their support?  
In what ways do people support you?

#### Cultural adherence

How do you fit in with your family?  
How do you fit in with your community?  
Do you ever have to change your behaviour to do this? If so how?  
Do you share similar beliefs and values to your family?  
Do you share similar beliefs and values to your community?

#### Time

How has the way you feel change as time has passed?  
How have you adapted as time has passed?

#### Sport/ Physical activity

What sport and physical activity do you do now?  
What are your reasons for doing/ not doing sport?  
What does sport mean to you?  
What does playing sport give you?  
What ways if any, did sport had a negative effect on your life before?  
What ways if any, did sport had a negative effect on your life after SCI?  
How often and how long do you spend doing this?  
What sport/ physical activity did you do before your injury? How much?  
What level were you at?

What were your reasons for playing/ not playing sport?  
What did sport mean to you?  
If you took up sport since SCI how has this affected you?  
If you stopped sport since SCI how has this affected you?

## **Disability**

### **Social Model**

Have you heard of the social model of disability?  
If so what are your views on it?  
In what ways does society restrict you?  
How do you overcome this?  
In what ways does your environment restrict you?  
How do you overcome this?  
Impairment effects

In what ways does your impairment affect you?  
What are the physical effects of your impairment?

### **Psycho-emotional disablism**

How does disability affect you psychologically?  
How does being disabled make you feel?  
How do other people make you feel?  
How do you think disability is stereotyped?  
Do you have any experience of this stereotyping?  
How did you react to this?  
Have you ever experienced disablism?  
How did you react to this?  
How did this make you feel?

### **Health/ Wellbeing**

How would you describe your health and wellbeing?  
How does your health and wellbeing influence your life?  
In what ways is it important/ unimportant to you? Examples of this?  
How do you improve your health and wellbeing?  
How has your health and wellbeing changed since becoming disabled?  
Why has it become more or less important?