

**The Storied Self:**

**The Effects of Spinal Cord Injury on Identity Narratives**

by

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## ABSTRACT

This study examines the effects of spinal cord injury on identity narratives and the role of narration in the transformation of self following the injury. The purpose was to uncover what the stories, told by individuals with a spinal cord injury, can tell us about the transformation of identity after a forced identity transition, a transition that is neither desired, anticipated or chosen. Using narrative analysis, five narrative types were revealed: 1) Second Chance, 2) Familial, 3) Transition, 4) Rehabilitation, and 5) Explanation. Three main themes evident within the narrative types included: personal identity, autonomy and control, and social identity pertaining to peer role and family. The findings revealed both personal narratives and reflections on experiences during three stages of transition – pre, during and post injury and how events from each of these stages were pieced together within a broader narrative that reflected participants' attempts to present and create a coherent identity. The study has implications for individuals who encounter moments of shifting identities while attempting to create a new self, as well as for practice where narration is seen as a viable option in adjustment and transition work with individuals. Findings take into consideration the influence and power of the social worker in the co-construction (narration) of stories post injury.

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## CHAPTER ONE

### An Introduction to Narrative Research

*Narratives are the device all humans use to make sense of their experiences, to assemble the pieces of their remembered past in a story that makes sense to them and explains who they are. Engel & Munger (2007, p. 86)*

### The Question - The Foundational Component

Sam was eighteen when he sustained a C7-C8 spinal cord injury. He was always athletic, involved in hockey since the age of seven. This game began like any other game. Sam suited up, skated on the ice and got ready to play, as he had done many times before. It was the second period and his team was down 3-1. His line was up. As he was skating down the ice, he caught a pass when out of nowhere he was checked by an opposing player. He was pushed into the boards head-first. As Sam lay prostrate on the ice, he knew his body felt different. In an instant, his life had changed. *He* changed. This is an example of a forced identity transition, a transition that was neither chosen nor anticipated. In a moment, his understanding of self shifted from being perceived as *independent to dependent*<sup>1</sup>; able-bodied athlete to someone with quadriplegia. Sam's identity was grounded in physical self, so how would he, or could he, reconcile who he was before the injury with who he would become?

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<sup>1</sup> I am aware that Critical Disability Literature (Gilson & DePoy, 2002; Hosking, 2008; Devlin & Pothier, 2005; Pfeiffer, 2005; May, 2005; Tichkosky, 2003; Hiranandani, 2005; Barnes, Mercer & Shakespeare, 1999; Brzuzy, 1997) views *independent* and *dependant* as subjective terms, often accompanied by ableist notions of ability. However, these are terms used by the narrators and I have chosen to use their language.

Identity, narrative and forced identity transition. How are they connected? Can abrupt, unanticipated experiences change a person's identity? What can the narratives of individuals in transition look like? I have an interest in unpacking these questions because for the past seven years I have worked with persons with spinal cord injuries (SCI), many of whom considered the injury to be life changing. I have heard stories of adjustment and transition told in the midst of difficult circumstances. It is through the telling of and listening to these stories<sup>2</sup> that I began to understand how identity is formed and transformed after such an event. These preliminary understandings prompted me to study the effects of spinal cord injury on the identity narratives, told by persons who lived through the experience.

My purpose was to answer two broad questions: what role does telling stories about the self play following a spinal cord injury and what can we learn from these stories with regard to transformation of self post injury? These questions were answered through the collection and analysis of narratives told by individuals with a spinal cord injury. The narratives pertained to three distinct stages of their lives: (1) pre-injury, (2) during rehabilitation and (3) post-injury. The findings revealed how events from each of these stages were pieced together within a broader narrative that reflected participants' attempts to present and create a coherent identity.

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<sup>2</sup> It is important to note that I use both narrative and story to describe the product of narration, where narratives can consist of a series of stories that retell moments in an individual's life (Engle & Munger, 2007).

## Definitions - A Narration of Terms

The key concepts pertinent to my research are identity, narrative and forced identity transitions. Each will be discussed at greater length in Chapter 2. It is important to note that the definitions cited in the literature can vary widely depending on the author, focus of the research and its purpose. For this study, I chose to apply definitions that are in keeping with the theoretical underpinning (postmodernist and social constructionist) and analytical purpose of what I was trying to understand (the effects of a spinal cord injury on identity narratives from the perspective of the teller).

### Identity (Self)

Vignoles (2011) defines identity<sup>3</sup> as “all aspects of the image of oneself as represented in cognition, emotion and discourse” (p. 404). For other authors, (Guidano, 1987; Gergen, 1991) identity is understood to have many dimensions. I focused on the three that were the most pertinent to this study. These three dimensions are: (1) identity as both personal and social; (2) stable and fluid; and (3) formative and transformative (McAdams, 2011; Bamberg, 2010).

Identity as *personal* refers to self-understandings that are derived from considerations of one's self as unique, whereas identity as *social* refers to self-understandings that are derived from considerations of one's self as similar and connected to other people. For example, one can identify as a hockey great (personal identity) and a member of the high school hockey team (social identity).

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<sup>3</sup> For the purposes of this study I will be using identity and self interchangeably.

Identity as *stable* means aspects of identity are present during all stages of identity development and remain consistent in the wake of change (e.g., self as positive, self as determined, self as independent) (Bamberg, 2010) whereas *fluid* refers to the parts of identity that change due to new experiences, context, influences and fluctuating circumstances (e.g., an understanding of self as able-bodied that changes to an understanding of self as person with a spinal cord injury) (Bamberg, 2010).

The *formative* dimension of identity takes into account the slow and steady development of self over the course of one's life, solidifying during late adolescence/early adulthood stages of development. These dimensions include stages of hope, will, purposes, competence and fidelity (Erickson, 1993). *Transformative* refers to how identity continues to develop though out life, after adolescence, to the extent that even some of these formed aspects can be altered (e.g., life changing event such as SCI). The notion of identity transformation challenges the idea that one's identity is achieved.

### **Narratives (Stories)**

Porter Abbott (2008) states that narrative<sup>4</sup> is the representation of an event or action or a series of events or actions. Complex narratives contain multiple events that are causally connected. A complex narrative, then, can consist of many simple narratives that have been pieced together in a particular way. Narratives often contain characters and plots that can inform the listener of the who, what, when, where and why of the story. The tellers, who in this particular study were persons with a spinal cord injury, created the

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<sup>4</sup> For the purposes of this study I will be using narrative and story interchangeably.

narratives by recounting their experiences of what happened before, during and after the injury.

Narratives can be understood to be mechanisms for identity construction and analysis (Bamberg, 2010) and can be especially revealing when they refer to momentous events that have altered a person's life (Lohne, 2007). The narrative when it is told as well as the meaning it conveys, solidifies the self, i.e., acts like a snapshot of one's identity at that particular moment (Lohne, 2007). In this way, the narration of lived experience can serve as the basis for identity construction.

### **Forced Identity Transition**

*Forced identity transition* is not a phrase that is widely used in the literature and consequently, it was difficult to find an appropriate definition. In this study, I used this phrase to refer to the dynamic process whereby experiences and events form and transform who a person perceives him or herself to be. These experiences and events and the resulting identity shifts are not chosen and in many cases are not desired. In a forced identity transition the individual is not the agent of change. Thus the question becomes: "What are the effects of the injury on the participant's identity?" For example, did this undesired injury change the participant's self understanding from "able-bodied" to "disabled", from someone who could walk to someone who sits in a chair? It is possible to imagine that a spinal cord injury would challenge one's understanding of ability and normalcy in relation to self.

## **Spinal Cord Injury (SCI)**

According to the Canadian Paraplegic Association (Nova Scotia, 2013), a spinal cord injury is defined as the severing or injury to the spinal column, which can result in complete or incomplete paralysis. Persons with paraplegia and quadriplegia are paralyzed in their extremities and in their torsos. Most persons with severe spinal cord injuries have a loss of sensation below the level of injury and loss of controlled function of the bladder and bowel. The injury can also affect sexual function, hand and arm movement, dexterity and in some cases, breathing and swallowing abilities. The degree of paralysis depends upon the level at which the spinal cord was injured. SCIs are classified as follows.

**Paraplegia.** The paralysis of the lower extremities and part or all of the trunk muscles as a result of injury or disease below the first thoracic vertebrae, T1. A person with paraplegia will typically have strong arms and hands but weakened legs and usually rely on a wheelchair for mobility. This is often accompanied by a loss of sensation in paralyzed limbs and other unpleasant side effects.

**Tetraplegia/Quadriplegic.** There are eight classifications of quadriplegia, also known as tetraplegia, in relation to spinal cord injuries, graded C-1 through C-8 and based on the affected vertebrae. The damage to the spinal cord generally causes impairment to the hands and arms. This is an addition to the symptoms listed above.

## Theoretical Disclosure

Now that I have established working definitions for the terms utilized in this study, I will explore its theoretical underpinnings. My work was informed by a postmodernist world view and specifically the meta-theoretical perspective of social constructionism. However, before I proceed I must provide full disclosure regarding the deliberate exclusion of alternate theoretical perspectives. Given that this study was grounded in forced identity transition, I chose not to incorporate critical disability theory as a separate theoretical perspective or discussion. While I recognize that the rationale for the use of narrative could be supported by disability literature, I did not want this study to shift the focus away from forced identity transition and drift towards disability identity, detracting from the overall purpose. There will be undertones of a social model of disability and some discussion regarding the use of terms and discourses (i.e. 'normal,' medical discourse, ableist binaries, and (in)dependence), but I will not address critical disability theory separate from post-modernism, narrative and identity.

## Theoretical Perspectives

**Social Constructionism.** Social constructionism challenges modernist notions of reality in that individuals are understood to create reality as opposed to discovering it. Berger and Luckmann (1971) suggests that our individual and collective understanding is acquired through social interactions and shared social processes. This shared understanding and knowledge is grounded in specific historical, cultural and local contexts (Fook, 2002; Mullaly, 2007). This knowledge is then communicated through

social interaction and social processes, shared through narration and expressed in narrative form. This shared knowledge may indeed be a *social reality* but individually we each have different perspectives on what that *reality* is. For example, we tend to pay attention to certain aspects of experience that are consistent with our views of reality and ignore the aspects that are not in agreement.

Even though we all actively participate in the construction of reality and its meaning, we are also constructing our own sense of identity in accordance with social systems. For example, structures, institutions, and shared social activities combined with taken-for-granted assumptions and infiltrated meanings, all contribute to the moulding of our shared reality (Mullaly, 2007). Therefore, while we are contributing to the social construction of shared knowledge, we are simultaneously constructing our own social reality. This represents a circular and discursive process whereby we are both influenced by and contributors to this reality (Mullaly, 2007).

However, it is important to unpack how broader relations of power influence the ways in which people construct their realities and discourses, “the ways in which we make meaning of and construct our world through the language we use” (Fook, 2002, p. 63). Fook (2002) states that power is often viewed as a commodity, where people either have it or they do not, which only contributes to binary thinking such as rich and poor, weak or strong, the powerful and powerless. This dichotomous way of making sense of the world, suggests that only those with power are capable of decision making, in turn denying individual agency on the part of individuals and groups who are defined as

powerless. Fook (2002) suggests, power is “not something that we possess, rather it is exercised” (p. 52). Power then is not static, but has the ability to change based on individual circumstances (Fook, 2002; Mullan 2010). Therefore, through critical engagement we can begin to recognize power imbalances as a part of a broader social context allowing for the (de)(re)construction of meaning, oppression and the experience of powerlessness. When adopting this perspective, one can better understand how the identified issue(s) and concern(s) are both a source and consequence of language and broader social context (Parsons & Swan, 2011).

**Postmodernism.** Postmodernism provides us with different ways of knowing that incorporate social constructionism. Fook (2002) proposes that postmodernism challenges the modernist claims that truth and knowledge exist as objective realities and presents a very different perspective on how knowledge is created. The goal is not to determine whether knowledge is the *real truth*; instead the idea is to accept it as a *truth* that currently reflects an individual’s experience. When exploring knowledge we must take into account influences and personal creations, recognizing that the majority of knowing is based on socialization (Herz and Johansson, 2011). As such, postmodernism maintains that all knowledge is socially constructed through language and discourse.

According to Fook (2002), language is not neutral, but rather is subject to personal experiences and discourses that in turn influence the meanings we attribute to it. She suggests that language is not simply words, but rather a powerful indication of the dominant values and beliefs that we possess (Fook, 2002). Language helps us make

sense of our experiences through narration, while discourses have the power to construct shared understandings, resulting in dominant discourses that privilege taken-for-granted meanings and beliefs. Postmodernism challenges the notion of fixed universal truths, which means dominant discourses and ideologies can be changed and interpreted accordingly. Each person then, has their own unique, socially constructed perspective or subjective sense of reality and truth. This constitutes a unique lens through which we interpret the world and our experiences, even those experiences and beliefs reflected in dominant discourses that infiltrate all aspects of society.

For example, while dominant ideologies prevail, each person has an individual subjective interpretation based on their sense of what is true, which is influenced by both one's personal history and the collective history they share as members of social and cultural groups. These elements predispose people to interpret common experiences differently. Fook (2002) states, because social context and individual experience are inextricably linked, "postmodernism provides a more detailed theoretical understanding of individual in context" (p. 13-14) and consequently, how social structures strongly influence everyday experiences and our subjective sense of who we are.

**Postmodernism and Socially Constructed Narratives.** This study was based on the understanding that narration is a unique, socially constructed, subjective process that speaks to what is real and what is true for each individual. The narratives reflect a unique perspective through which the participants interpret the world and their

experiences, even those experiences and beliefs reflected in dominant discourses, providing a detailed understanding of the individual in context (Fook, 2002). As a result, narratives are influenced by the dominant categories and structures in which they are placed (Fook, 2002).

For example, the medical discourse can dominate spinal cord injury narratives in that it totalizes the individual based on injury (e.g. quad, para). The medical discourse is based on modernist notions of impairment, abnormality, restriction and inability to perform. The discourse is rooted in the biological perspective and has led to a spinal cord injury being viewed as merely a bio-medical product. This bio-medical view focuses on 'normality,' striving to 'fix' or 'cure' people with differing abilities. Here the individual is seen as a patient, who has a medical diagnosis that can be explained, treated and addressed through objective truth and knowledge. The medical discourse can infiltrate personal narratives in that, "The way individuals identify, order and come to put meaning into events, determines how they shape their stories" (Roscoe, 2011, p. 5). The resulting impact can be that those with a spinal cord injury conclude that there is something wrong with them.

While the medical discourse is intrusive, it is not always the dominant discourse for every individual. Through the process of narration, the individual has the ability to share their experience differently, where the injury does not define them. Through narration they reclaim their voice in telling stories indicative of a different discourse using language that reflects their reality, truth and meaning.

Stories, then, are understood to be the subjective reconstructions of a person's experience, reflecting his or her reality. These stories represent specific elements of the teller's experiences that are selectively drawn together at a precise moment in the teller's life told to a specific listener/audience for a particular purpose (Wosket, 1999). When people construct their narrative, they are also providing their own analysis of that experience. The narratives are contextually and ideologically based, rather than simple descriptions of past events. As such, the teller is incorporating his or her own views, beliefs and assumptions in the construct of the narrative (Ryan, 2006). Ryan (2006) states, "Post-positivist epistemologies focus more on the range of explanatory devices that people use to understand a situation or event" (p. 104) producing a "limitless number of accounts, deepening on the situation and relations" in which the narrative is told (Ryan, 2002, p. 3).

### **Personal Investment in Stories**

As previously mentioned, for the past seven years I have practiced social work with persons living with a spinal cord injury. I have witnessed them undertake the onerous task of transitioning from a life that was once somewhat predictable and familiar, to a life that was suddenly filled with difference, change and in some cases, uncertainty. I have listened to their narratives as they struggled to create and reflect self, trying to find meaning in the midst of transition. I have come to realize that each individual has a story and by sharing these narratives the individual situates self. These narratives are not always predictable, consistent or linear. Sometimes they appear

contradictory, fluid, and unfamiliar. This is what makes narratives so intriguing. The teller pieces together their experiences, forming a wonderfully rich narrative of self. So how, then, do these rich narratives represent forced identity transition and consequently, what are the effects of spinal cord injury on identity narratives?

### **Rationale for the Study**

Most of the literature regarding spinal cord injury concentrates on adjustment outcomes, quality of life and coping (Dorsett, 2001). According to Dorsett (2001), this research on adjustment has focused on a narrow range of factors, such as poor medical prognosis, barriers to active community participation, rehabilitation, coping, empowerment and medical complications (e.g., skin issues). While a great deal of interesting and valuable research has been conducted, Dorsett (2001) contends that much of it has “failed to adequately account for the complexities of the process and the vast array of variables that impact on adjustment” (p. 89). One noticeable gap in the literature is the consideration of identity transition as an adjustment variable and few studies, if any, used narrative data *and* narrative analysis to explore transition and identity with this population (Dorsette, 2001; Lohne, 2009; Valvano, 2012; Yoshida, 1993).

In this study, I examined narratives in connection to identity, specifically understanding narrative as a reflection of self and revealing how self is constructed. As such, I presented an opportunity for persons with spinal cord injury to tell personal narratives that reflected their identity while living with an injury. The storytelling was a collaborative process between teller and listener. The tellers shared how the SCI

affected, changed, shifted and challenged their understanding of self, and as the listener, I became a collaborator and co-author in that story as it was shaped by my questions, the context of my study and my experience. The resulting narratives provided the data from which to explore what forced identity transitions look like and how they are experienced. Both the act of narration and the narratives produced offered the opportunity to disrupt the dominant medical story and create genuine dialogue.

In this study I also looked at narrative in terms of experiential meaning, temporality and sociality. With regard to meaning, I looked at *how* and *why* the stories were told and for *what purpose*. The *how* was not simply unpacking the linguistic qualities (i.e. the pauses, frequency of particular words, tone and volume), but rather how the teller positioned themselves in the story (i.e. active, passive). I explored the *meaning* behind what was said, *why* they chose to share one story with me and not another. *Why* the story evoked a certain reaction for the narrator and *why* the story was told in relation to questions regarding self. *What* was the purpose of telling one story in relation to another? All three helped me understand the importance of narration in identity transition and the role of narration in creating interpretations that are personally meaningful. By studying the *how*, *why* and *what* I was able to see that:

People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. (Connelly & Clandinin, 2006, p. 375)

Experience, then, can be understood in terms of temporality and sociality. *Temporality* means paying attention to past, present and future, people, places and things. The *sociality* of narrative pays attention to the personal and social conditions under which events and experiences are unfolding, including the teller-listener relationship (Connelly & Clandinin, 1990). By studying narrative in this way, I was exploring the function of storytelling as a way of conveying meaning (Bruner, 1986), while acknowledging the complexity of identity narratives.

### **Justifying the Use of Narrative Research**

Narrative research allows for the exploration of an individual's life through the sharing of stories focused on personal experience (Bell, 2003; Clandinin, 2007).

Narrative research also requires researchers to utilize reflexivity, as they participate with the narrator in the construction of the narrative and its meaning. Reflexivity is a dynamic process of interaction *within* and *between* the listener and the teller, *and* the data that inform decisions, actions and interpretations (Hertz, 1995). This means the listener and the teller have a conversation about experience while simultaneously living in the moment (Hertz, 1995). Thus, reflexivity produces research that addresses *what* is known as well as *how* it is known, actively constructing interpretations rather than *facts* or *truths* (Hertz, 1995). According to Riessman (1993), narrative research is an effective way "to undertake the systematic study of personal experiences and meaning, how active subjects have constructed events" (p. 78).

The purpose of narrative research is to *understand* a phenomenon or experience rather than formulate a logical or scientific explanation (Kramp, 2004). As a narrative researcher I had a responsibility to *interpret* rather than *explain* the individual experiences that were told to me (Connelly & Clandinin, 1990). For example, this study offered individuals with a spinal cord injury the rare opportunity to share their experiences related to their understanding of identity. In turn, it was my job to take those stories, discern their meaning and present them in a way that stayed true to the tellers' intentions.

The crux of narrative research is the participant. This type of research privileges the storytellers because it is through their telling, rather than through the researcher's observations that we come to see life as experienced (Creswell, 2007). The narrative research process acknowledges the researcher's power and has parameters and guidelines in place to curtail that power so that the focus remains on the storyteller, the study participants. This is evident in the layered and detailed interview process, analysis and, delicate and thoughtful presentation of findings. Narrative research provides an opportunity for storytellers to organize their experiences into a story, which gives them shape and permits the experiences to be shared. For persons with a spinal cord injury, participating in narrative research can become an outlet for telling alternate stories that are often stifled under the heavy burden of medical discourse.

The operational aspects of narrative research reflects both process and product; that is, telling the narrative is the means of data collection and the narrative itself is the

form of data gathered. Narrative research is not merely the act of listening for events and actions, or a series of anecdotes (Kramp, 2004). Rather "it is a perspectival construction that enables you to see differently, to move beyond the particular and the generic" (Kramp, 2004, p. 7). Through the process of telling (collection), transcribing, and analyzing these stories (the product) are presented in a unique way.

### **Summary**

My study answered two broad questions, what role does telling stories about the self play following a spinal cord injury and what can we learn from these stories with regard to identity transformation. Given my social work background and professional ideology, I approached this study from a postmodernist worldview, specifically grounded in the meta-theoretical perspective of social constructionism that have particular understandings of reality, truth, knowledge, language, and discourse. I argued that this combined theoretical approach and narrative research are well suited in that both allow for the inclusion of storyteller perspective, lived experience, multiple truths and meaning creation.

## CHAPTER TWO

### **A Story About Identity and Narrative: A Literature Review**

*Our narrative identities are the stories we live by.*  
- McAdams, Josselson & Lieblich (2006, p. 4)

#### **Stories About Identity and Narrative**

This chapter will focus on reviewing theoretical literature on identity narratives, with an added component of disability identity, specifically pertaining to persons with spinal cord injury (SCI). First, the chapter will consider the concepts of identity and narrative separately, highlighting the three main characteristics of each that are pertinent to this study. This will be followed by an examination of identity narrative as a combined concept. Lastly, I will present a select sampling of representative studies that draw on all or some of the same concepts of identity, narrative and forced transition that I have selected. This sampling will include studies from Riessman (1990), Lohne (2008), Yoshida (1993), Sparkes and Smith (2005), and Valvano (2012). Since the definitions of identity and narrative have been provided in Chapter 1, this chapter will act as an extension, expanding the discussion on the formation of identity, narrative, identity narrative and disability identity.

#### **Exploring Identity Narratives**

I will begin by defining identity and narrative separately, given the close connection between the two concepts. While identity and narrative can be viewed as interdependent, they are different with regard to form, purpose and product. For

example, identity does not always take the form of a narrative and similarly, the purpose of a narrative may not always be to reveal processes of identity construction and development.

### **What is Identity?**

In the literature, a broad understanding of identity seems to be expressed in similar theoretical terms, yet specific definitions vary according to author. For the purposes of this paper I will be following Bamberg's (2010) definition of identity. Bamberg (2010) defines identity as "a label attributed to the attempt to differentiate and integrate [self] along social and personal dimensions" (p. 4). While identity has many characteristics, I am choosing to highlight three in keeping with the definition presented above. They are: 1) individual and social, 2) stable and fluid, and 3) formative and transformative. Identity begins with the individual's ability to differentiate between self and other (individual and social), and includes elements of both "continuity and change" (p. 4), also known as stable and fluid (Bamberg, 2010). This fluidity allows for the formation and transformation of identity over time.

**Identity as Individual and Social.** Identity is both personally and socially constructed. Individual identity may include goals, values and beliefs, with a focus on individual agency (Vignoles, Schwartz, & Luyckx, 2011). There are also social ways of understanding each other in that we are similar to others, yet we remain unique. Identity, then, becomes based on practices "in which versions of self differentiation and integration are negotiated with others, tried out, rejected or accepted... [as] part

of a continuous navigation process” (Bamberg, 2010, p. 7). This form of personal agency is dynamic and fluid, and contributes to transformation.

Social identity can be assigned, such as spouse, child, father, mother, teacher, and so on. This form of identity refers just as much to the processes of how roles are defined and interpreted as it does the assigning of role through social interaction or circumstance (Vignoles, Schwartz, & Luyckx, 2011). The meanings assigned to social identity often intersect and infiltrate personal identity, as it is nearly impossible for the two to exist independent of each other (e.g., father, SCI, male, athlete, partner) (Bamberg, 2010). Furthermore, as Vignoles, Schwartz & Luyckx (2011) explain, “identities are inescapably *both* personal *and* social not only in their content, but also in the processes by which they are formed, maintained and changed over time” ( p. 5).

**Identity as Stable and Fluid.** According to Vignoles, Schwartz, and Luyckx (2011) there is debate over whether identity is stable or fluid, but they contend these two aspects can be reconciled by focusing on the individual and contextual aspects of identity formation. For example, what are often seen as stable aspects (e.g., father, mother, sister, brother), may appear so only because of the efforts put into maintaining these roles and the context in which they are placed. However, the presence of stability does not mean the absence of fluidly. For example, “identity stability may be the outcome of successful processes of identity maintenance or defence” (Vignoles, Schwartz, & Luyckx, 2011, p. 10), yet be subject to fluidity as a result of circumstance.

This is often the case following a forced identity transition when understandings of being the *same but different* occurs.

These understandings of being the *same but different* occur during shifts in context (e.g., SCI), which result in shifts in identity. However, fluidity is not meant to imply a lack of agency whereby individuals are passive recipients, at the mercy of social and personal context. Rather, people tend to choose contexts and experiences that have meaning and can solidify who they are, which contributes to both the stability and fluidity of identity (Vignoles, Schwartz, & Luyckx, 2011). They propose that the fluidity of identities is influenced by identity motives, which are defined as “tendencies towards certain identity states and away from others, which guide the processes of identity definition and enactment” (Vignoles et al., 2011, p. 405).

The meanings people assign to identity motives are influenced by the individual, social, cultural and historical building blocks needed to construct identity. Even as people try relentlessly to preserve self, they may not see what motivates identity constructions. So, while “identities themselves may be constructed rather than ‘real,’ the psychological process and social actions by which people construct, maintain and defend them are absolutely real, as are the consequences” (Vignoles, 2011, p. 405). One example of an identity motive, is the motive of *continuity*, the need to feel a connection between one’s past, present and future identities, which is established to deal with the discontinuity in one’s life. In this instance continuity is

understood to be the thread that holds everything together despite the change, as opposed to being equated with consistency or absence of change.

**Identity as Formative and Transformative.** Identity formation consists of diachronic and synchronic processes, meaning identity is formed over time and at specific points in time. Individuals become active agents when they control such construction (Bamberg, 2010). This relates to Bamberg's (2004, 2010) and Yoshida's (1993) thoughts on transformation and identity creation. The authors suggest that when traumatic or unpredictable change events occur, one begins to search for, construct and maintain meaning (Bamberg, 2004; Yoshida, 1993). This transformation can be revealed in narratives and facilitated by narration.

That identity can be formed and transformed underscores the complexity of identity, in that an individual can see themselves as the same person they used to be, yet in the same instance see themselves as different and new (Bamberg, 2010). Yoshida (1993) suggests that the formation and transformation of identity can be conceptualized as a pendulum whereby the dynamic nature of identity (re)construction is represented as a "dual directional process." (Yoshida, 1993, p. 220) The process occurs, for example, when the identity of an individual with an SCI fluctuates between disabled and non-disabled self understandings rather than in a trajectory in any one direction.

This notion of a multifaceted identity can pose a problem when trying to negotiate a unity of self during transformation. In some cases, various aspects of an

individual's identity may be seen as contradictory (e.g. physically active yet with very limited mobility). However, there are two ways to unpack this. First, while the two aspects of self are in conflict, "they are still part of a single, overarching identity" (p. 6). Second, the individual might experience her or himself as having two identities and have difficulty with unity of self (Vignoles, Schwartz, & Luyckx, 2011). When unity of self is challenged, narratives are constructed to reconcile inconsistencies in identity, while preserving some form of continuity during transformation.

### **What is Narrative?**

Narrative can take many forms and serve many purposes and as such, there are many ways of defining narrative. For the purposes of this study, I will be using a combination of Lohne's (2007) and Bamberg's (2010) definitions of narrative. For Lohne (2007), narratives are more than the anecdotal recalling of memories. "Narratives give rise to learning new lives" (Lohne, 2007, p. 72). As such, narratives become mechanisms for identity formation and analysis (Bamberg, 2010). For example, the question, "Who are you?" can often be answered using a narrative that is more than a life story outlining happenings and events using linguistic qualities.

As with identity, narrative too has many characteristics, three of which are narratives as 1) purposeful; 2) dynamic and changing; and 3) constructive and reconstructive. These characteristics illustrate how narratives aid in identity formation, especially when things happen to individuals that drastically change their life course, and ultimately, the very fabric of who they are (Bamberg, 2010; Lohne, 2007).

Narratives can consist of a series of stories that retell moments in an individual's life that resulted in identity transformation(s). These stories draw on past experiences, perceptions and feelings, while making sense of life lived, piecing together a narrative that explains who the individual is (Engle & Munger, 2007).

**Narrative as Purposeful.** Narratives are purposeful, in that they are told for a specific reason at a specific time, which also makes them contextual. Given that the purpose of a narrative is often interwoven with context, Bamberg (2010) offers several questions that assist in unpacking the purpose and meaning behind a narrative. What does the narrative stand for? How are narratives consistent? How are narratives different? What does this narrative not tell us about x, y, z or the parts that are consciously absent? The answers to the questions help us discern the purposefulness behind the narration.

Narratives can be purposeful in that they help situate self. Often narratives present a desirable self as a way of managing "spoiled identities" (Goffman, 1963 in Riessman, 2002, p. 700) or of representing a "preferred self" (Riessman, 2002, p. 700). A spoiled identity refers to an identity that would cause a person to experience stigma and would disqualify them from full social inclusion (Goffman, 1963). This stigma can come in many different forms and often, people who have been stigmatized feel as though some aspect of them is tainted, detracting from their whole self, leaving them feeling devalued, different and in some cases, rejected. Examples of spoiled identities could be understood as belonging to a racial minority group, being lesbian, gay,

bisexual or transgender, based on body size, and specifically relevant to this study, spinal cord injury. The stigma that results from a spoiled identity “constitutes a special discrepancy between virtual and actual social identity” meaning an incompatibility between who we think we are with who everyone else deems us to be (Goffman, 1963, p. 2). A preferred self is the self we wish to be or the self we think we should be (Riessman, 2002). In either case, narratives are situated stories that inform the listener about who the teller is or wishes to be (Riessman, 2002).

Bamberg (2010) and Kramp (2004) would both agree that because narratives are told for a specific purpose, they should not be the subject of restrictive approaches that aim to simply cite the chronological ordering of events, speech patterns or the absence and presence of main characters. Bamberg (2004) states, “I have become increasingly dissatisfied with strait-jacket controls of ‘cognitive revolution’ when it comes to exploring the lives of ‘real’ people, and the telling of ‘real’ stories in ‘real’ contexts” (p. 214). He emphasizes that the purpose of narrative research is to figure out *why* the stories are important to individuals (Bamberg, 2004).

**Narrative as Dynamic and Changing.** One's narratives are dynamic, constantly being adapted to new experiences, renegotiated to accommodate new meanings and grounded in interaction. By unpacking the purpose of narratives, we can begin to see how they are useful for individuals working through challenging circumstances (Engle and Munger, 2007). Narrative can also be understood in the light of social-construction (Bamberg, 2004), how people see the world and their place in it. This requires one to

pay close attention to the manner in which narratives are “rhetorically and argumentatively organized” (p. 221). This can be achieved by following the “interactive subtleties and rhetorical finessing that are part of the daily expression of attitudes, evaluations and assessments” (pp. 221-222).

Kramp (2004) says stories are flexible. This flexibility means that the process of narration becomes a way of interpreting the experiences and events, rather than setting out to prove that they are truth or reality (p. 107). What is *told* is of significance because it helps us understand the meaning of each narrative, a byproduct of narrative knowing (p. 108). Narrative is:

not merely a listing of events or actions, nor simply a series of anecdotes. Rather it is a perspectival construction that enables you to see differently, to move beyond the particular and the generic, aware of what each says to enrich the other (Kramp, 2004, p. 109).

As Sparkes and Smith (2005) state, “regardless of whether life is a narrative or narrative is a life, it would seem that narratives do matter...in the face of disruptive and turning-point moments in their lives” (p. 87).

**Narrative as Constructive and Reconstructive.** As mentioned above, narratives are situated stories that tell the listener a great deal about one’s identity (Riessman, 2002). Stories are constructed and reconstructed to help one make sense of new experiences and there is no better example of how to understand this construction and reconstruction than Frank (1995). Frank (1995) argues, “in both listening to others and telling our own stories, we become who we are” (p. 77). Frank (1995) suggests that

these stories can take different forms, referred to as "narrative types," which he defines as follows:

A narrative type is the most generalized storyline that can be recognized underlying the plot and tensions of particular stories. People tell their unique stories, but they compose these stories by adapting and combining narrative types that culture makes available (p. 75).

Frank's (1995) work is particularly relevant to this study because he writes about the effects of illness and injury on storytelling and consequently the authoring of identity. He understands the body as an instrument through which stories are told (Frank, 1995). In doing so, Frank (1995) reveals how illness (and injury) can disrupt old stories, becoming a call for new stories in the reclaiming of self. These new stories can take the form of narrative types. Frank (1995) identifies three: The Restitution Narrative, The Chaos Narrative and The Quest Narrative.

*The Restitution Narrative* has a plot that consists of a basic storyline: "I was healthy, now I'm sick, tomorrow I'll be healthy again" (Frank, 1995). Healing is treated as a "normal condition" from which people can be restored. This need for restoration is further influenced by the expectation that people want to hear restitution stories. We like stories of recovery and overcoming insurmountable odds. The narrative becomes a learned story, told from the perspective of the individual and the institution, where all reflect the desire to be well and stay well. People are provided with models, preferred narratives, that reflect the story one should tell, while shaping the culture of illness (Frank, 1995). The consequences of such a narrative are complex where the

expectations of the "sick person" become institutionalized, validated, functional and internalized (Frank, 1995, p. 81). This is a powerful narrative that not only represents the expectations of the medical community regarding the person who is sick, but also what society expects from the medical community in turn. This narrative is often grounded in ableist assumptions where being *able-bodied* and *healthy* are the norm and that people who have disabilities or illness must strive to become that norm. A disability or illness is thus, inherently, a "bad" thing that must be overcome. The ableist worldview purports that disability is an error, a mistake, or a failing, rather than a simple consequence of human diversity (Campbell, 2009). The idea of Restitution becomes a narrative about control and normalizing - controlling the body, controlling the circumstances and controlling predictability. This narrative is about normalizing the illness, interruption and response. The identity becomes restored and entrenched while the body becomes disciplined (Sparkes & Smith, 2005).

*The Chaos Narrative* is the opposite of restitution. In these narratives life is imagined as never getting better (Frank, 1995). These narratives are often hard to hear as they do not tell the accepted or "proper" story. There is no narrative order; instead each narrative is separate and does not lead to another. Chaos narratives go against the modernist notion of progress and remedy, "revealing vulnerability, futility and impotence" (Frank, 1995, p. 97). Ultimately, the chaos narrative reveals the "wounded storyteller" (Frank, 1995, p. 98) through an "anti-narrative" of sorts. The chaos narrative can be hard to hear in that the speech pattern is disjointed, interruptions are

numerous, chaos is embedded and it is void of defined purpose (Frank, 1995). Here the self is fragmented and the body is chaotic (Sparkes & Smith, 2005). However, the chaos narrative needs to be honoured despite the discomfort. These narratives need to be accepted so new narratives can begin, while keeping in the mind the importance of acknowledging them without rushing to move on (Frank, 1995).

*The Quest Narrative* meets suffering head on (Frank, 1995). Illness and injury is seen as a journey, even though the quest may not be clear or defined. Quest narratives give voice to the individual so that they can tell their own story, from their perspective offering alternate ways of living with illness and injury. The journey takes place in three stages: (1) departure, (2) initiation, and (3) return (Frank, 1995). It begins with acceptance, followed by a road of trails and transformation, ending with narratives marked by the experience of having been ill. These narratives reflect an understanding of the illness or injury as a way of gaining experience, an opportunity to be reborn, suggesting a significant disruption in life. Here the self may begin as fragmented but end with a narrative where “the past is the past” and identity becomes transcendent (Sparkes & Smith, 2005).

Although the consequences of each narrative type may vary, the end result is still stories that seek to define past, present and future identities. Furthermore, narrative is constantly constructing and reconstructing self in the midst of a fluctuating circumstance, as evident in Frank’s (1995) work outlined above.

## What are Identity Narratives?

So, what then are identity narratives? Dunn and Burcaw (2013) define an identity narrative as “the personal, evolving story of the self that an individual consciously and unconsciously creates to bind together many different aspects of self” (p. 148). Identity narratives allow the individual to take a more reflective stance on determining self, offering a space where identities are negotiated, which can be critically reflected in the process of narration (Bamberg, 2010; Dunn & Burcaw, 2013). Bamberg (2010) states that “reducing narratives to what they are *about* irrevocably reduces identity to be depicted at the representational or referential level of speech activities” (p. 5). This reduction discounts the very aspects of everyday life that are continuously being constructed, “formed and performed” (p. 5), leaving no room for negotiation or discontinuity. For McAdams (2011), we make sense of self through an identity narrative that is not “set in stone” but rather never really finished (p. 100).

**Identity Narratives as Stories We Live By.** McAdams (2011) proposes that our identity narratives are the *stories we live by*. They are “life as reflected instead of life as lived” (p. 12). He goes on to say, identity narratives are the internalized and evolving story of the self that a person constructs (McAdams, 2011). Even though identity narratives are understood to be a subjective and historical account of life, they allow the individual to elicit experiences that have meaning, thus contributing to identity formation (McAdams, 2011, p. 100). That said, there are many contextual factors that influence one’s narrative, such as cultural norms and alternate discourses. Despite the

ever-changing nature of identity narratives, they are still used to make sense out of lived experience as people seek meaning as opposed to mere social performance.

**Identity Narrative as Formed and Performed.** Identity narratives do not need to be the grand narrative, that is a “totalizing narrative that makes sense for all time in any given person’s life” (McAdams, 2011, p. 103). Rather, they represent a sub-narrative of sorts, offering a sense of cohesion and purpose in that instance. Identity narratives formed and performed, assign purposefulness that often emerges “during a period of life course that will forever retain a special salience in memory” (p. 107). Yet, even then these stories remain a work in progress. Even as identity narratives shift and change, they have “longitudinal continuity” allowing for “some degree of unity and purpose” (p. 108), a “narrative rendering of selfhood” per se (McAdams, 2011, p. 103). According to McAdams (2011), identity narratives “never completely descend into literal realism” (p. 106). Rather, “if they are to inspire and integrate, the stories we tell ourselves about who we are and how we came to be must retain their mythic qualities” (p. 106). Individuals select, draw on, incorporate and distort past events to connect and support aspects of current and future self, while remaining factual.

**Identity Narratives as Lived Experience.** In much the same manner, there is a common assumption that identity narratives are the culmination of significant life events that are interpreted and given meaning, and contained within recognizable themes and patterns (Pals, 2006). For some, these events interrupt the storyline while for others, they provide stability and unity. It is the difficult experiences that often test

the identity one has authored, challenging the coherence, purpose and meaning of the identity narrative itself. Pals (2006), taking a logical approach to narrative, suggests that the coherent narration is “positively associated with life satisfaction” (p. 1083), where there are a “high degree of redemption sequences” (p. 1083) (i.e., negative experience leading to positive outcomes). She discovered that when “narrative identity contains coherent positive resolution of experiences that have challenged identity in the past, the self is strengthened by this memory and made more resilient to face new experiences” (Pals, 2006, p. 1098). This suggests that difficult life experiences affect future identity development. This also suggests that individuals have the ability to construct identity narratives that incorporate both the difficult and positive experiences in such a way that they are able to adjust to this evolving identity narrative.

### **The Role of Identity Narratives in Experiences Pertaining to Disability**

The role of narration in identity creation is particularly pertinent when adding the element of difficult life experiences (e.g. SCI). Pals (2006), Lohne (2007), and Dunn and Burcaw (2013) all contend that difficult life experiences challenge the narrative construction of identity. In some instances it produces a narrative that incorporates both interpretations of pre disability self with post disability self, allowing for a duality of sorts. The actual construction of these narratives provides the opportunity to revisit experiences while living in the present, both becoming central to individual functioning (Pals, 2006) and reconciling all aspects of self while providing meaning and purpose.

## **Disability Identity in Narrative Form**

Dunn and Burcaw (2013) expand the definition of identity narrative to include disability identity, adding the component of connection to and affinity with other persons with disabilities. This definition helps make sense of the different aspects of self that may or may not include disability. When unpacking disability and self, Dunn and Burcaw (2013) pose a very important question, at what point “does disability identity supersede other identities,” (p. 149), or does it? They discovered that living with a disability can be a positive source of personal and political identity resulting in a desire to be “recognized and treated like everyone else within a group or society” (p. 149). Disability can also aid in formulation of “perceived identity as capable self” (Engle & Munger, 2007, p. 87). While commonalities exist among individuals living with disabilities, it is important to recognize the complexities of individual experience and refrain from generalization.

**Coping and Succumbing in Disability Narrative.** To further illustrate disability identity, Dunn and Burcaw (2013) present a framework that outlines coping versus succumbing. *Coping* “emphasizes existing or potential assets while broadening scope of values beyond those compromised or never realized precluded by disability” (p. 151). *Succumbing* is seen as “denying or trying to mask disability, by idolizing normality, seeking the impossible, emphasising (sic) deficits linked to disability” (p. 151). Coping and succumbing are often present in the “beliefs storytellers develop and rely on to understand, navigate and share their life experiences with others” (p.

151) and become vital in the creation of disability identity narratives. These narratives are grounded in creating self-worth and valuing the qualities the storyteller had before disability onset.

Lohne (2007) adds that coping is aided by the processing of experiences, where reconciliation follows a serious turning point. Lohne (2007) states, how “one understands experiences” gives rise to different ways they learn to live their new lives (p. 73). While there has been research conducted on narrative identity in general, both Lohne (2007) and Dunn and Burcaw (2013) would agree that we need to gain a better, deeper understanding of the experiences of persons with disabilities, hence disability identity.

**Multiple Selves in Disability Narrative.** By melding disability identity with narrative, individuals can begin to address differing aspects of identity, which Yoshida (1993) calls “predominant identity views” (p. 222). These predominate identity views encompass: (1) former self; (2) supernormal identity; (3) disabled identity as total self; (4) disability identity as aspect of total self; and (5) middle self. The *former self* represents the basis for reconstruction while the *supernormal* identity engages in activities of an extraordinary nature, for example, activities beyond one’s natural ability. The *disabled self* as total self is presented as being associated with “negative” identity (p. 227) whereas disability as *part of self* is non-encompassing. The *middle self* is where the identity rests between both aspects of self, disability and non-disability. However, for many, the movement between all five levels depends on individual

experiences and how one processes those experiences. For instance, an individual who considered himself to be an athlete before injury, can find ways to maintain that identity after injury.

### **Spinal Cord Injury and the Role of Identity Narratives in Transition**

Sparkes and Smith (2005) define spinal cord injury as a “major disruptive life event that instigates a multiplicity of difficult and complex issues” (p. 81). It can also be considered a forced transition as opposed to a difficult situation (Lohne, 2007), in that it is a sudden and traumatic incident, resulting in injury. The individual experiences major changes while being forced to confront shock, suffering and repercussions. When such a momentous event occurs, one's narrative and one's identity is altered in an instant. During that “turning point moment” (p. 83) where, who one was, who one is and who one will become converges in an unfamiliar identity narrative (Sparkes & Smith, 2005).

**Formation and Transformation Post-SCI.** These identity narratives give meaning as they function to provide structure to current identity. Sparkes and Smith (2005) state that “a self in time can only exist as a narrative construction” (p. 82). This construction encompasses many facets of self and numerous identities, often worked and reworked, revised and created. These identity narrative constructs guide the actions of the individual, fostering an understanding of oneself as “embodied” (p. 82). In turn, this narrative creation can be used as a learning opportunity, where “experiences of

suffering depend on the meaning the individual gives them and that meaning is an attempt to explain what has occurred" (Lohne, 2007, p. 69).

For example, Sparkes and Smith (2005) interviewed men who sustained a spinal cord injury during rugby, and found that certain metaphors, notions of time and messages of hope, correlated with different types of narratives as presented by Frank (1995). Similarly, Lohne (2007) found themes of shock, survival and miracle/luck after interviewing newly injured individuals in a rehab facility. In both cases, many identities became fashioned to the idea of restitution, making a comeback of sorts.

In other instances, the narratives were enveloped with chaos where one never gets better, represented by Freeman's (2000) notion of "narrative identity foreclosure" (p. 85). Narrative identity foreclosure occurs when an individual's narrative is no longer adequate or meaningful, and in some instances, sets the stage for "restarting one's life story" as possibility for "self renewal" (Freeman, 2000, p. 81). For others, it was the quest, meeting the effects of the spinal cord injury head on. In this case, they sought to understand it as a journey, as an experience from which they had something to learn. Sparkes and Smith (2005) state that "the reborn metaphor suggests that a serious disruption in life's prospects and expectations can offer some people the opportunity to remake themselves" (p. 85).

**Expressing Multiple Selves Post-SCI.** Valvano (2012) discovered that the relationship between narrative and identity for persons with a spinal cord injury became a fundamental way of expressing oneself. Valvano (2012), referencing

McAdams (1995), says that "one's identity is one's storied self; identity and self are not equivalent, but once the person has created a unified and purposeful story, he or she has achieved identity" (p. 5). These stories are continuously revised, incorporating new experiences, meaning and events as a way to maintain some thread of continuity while remaining flexible in the presence of disability. For people with spinal cord injury, challenges such as pain, skin issues, depression and underlying health concerns, may hinder one's efforts to create this sense of unity.

### **Narrative Studies on Forced Identity Transition**

Now that identity, narrative and identity narratives have been defined and characterized, this section will highlight a review of literature pertaining to narrative studies regarding forced identity transitions. This is a select, representative sample and is not intended to be an exhaustive list of available studies. The purpose of this section is to indicate a foundational understanding of past narrative identity studies as they relate to this study.

Riessman (1990) was one of the first to study identity transformation by using narrative analysis to understand the experiences of divorced spouses. She ultimately unearthed how narratives reveal layered structural variables, specifically how people experience these variables. For example, Riessman (1990) discovered that participants used the interview as a way to reflect on what they thought led to marital breakdown as well as to create meaning pertaining to the experience of being divorced. Each interview was narrated differently depending on the perspective of the teller, allowing

Riessman (1990) the opportunity to examine how the stories were told. She discovered that the telling took four forms: storied (linear and progressive), habitual (routine recounting), hypothetical (what would likely happen under specific circumstances) and episodic (what did happen, displaying significance).

Riessman's (1990) findings informed my study in two ways. First, she re-envisioned the importance of what many researchers considered storied digressions. What seemed like long, meandering stories, were actually deep rooted narratives of naturally occurring conversations filled with meaning, experiences, challenges and human relationships. Secondly, Riessman (1990) resisted the urge to contain narratives, going against the restrictions of conventional storytelling. By not containing narratives, she could reflect on and respect participants' ways of organizing meaning in their lives (Riessman, 2000). By so doing, Riessman (1990) led the way in conducting research that fostered the storyteller perspective.

In Yoshida's (1993) study, entitled *"Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury,"* she presents the reconstruction of self as a pendulum, one that is dynamic, negotiating between disabled and non-disabled self. She concludes that there are five identity views ranging from former self to disability identity as total self. She discovered that identity views are influenced by several experiences from loss to continuity. The result was that identity is both stable and fluid, and subject to transformation in the wake of illness or forced identity transition.

Yoshida's (1993) study was important and pertinent to my study for three reasons. First, she acknowledges aspects of former and current self in identity formation post-SCI, which is illustrated in a dual directional process. Secondly, Yoshida recognizes the layered consequences of disability on identity and how that influences how one sees themselves post-SCI (e.g., disabled – non-disabled). Thirdly, she acknowledges the effects of a spinal cord injury on identity. For example, she found that the effects of the spinal cord injury were often influenced by age, anger, personal self, social self, physical self, agency, adjustment and one's ability to merge identities.

As mentioned in the previous section, Sparkes and Smith (2005) studied the experiences of men who sustained a spinal cord injury as a result of a sport related incident. These forced identity transitions were not only disruptive but resulted in difficult and complex issues infiltrating all aspects of the person's life. They looked specifically at the task of restoring life and identity post injury. What they found was that the narratives types shared by the men corresponded with Frank's Restitution, Chaos and Quest narratives (see "What is Narrative?" section on page 22 for further detail).

Sparkes and Smith's (2005) findings informed my study in two ways. First, they present findings that illustrate the dynamic process of storied selves and identity formation. Specifically, they identified the importance of narration (storying) in the authoring of identity post-SCI, as a way of expressing what has been experienced in relation to challenge and perseverance. As such, narratives do matter in the lives of

those 14 men. Secondly, they concluded that these stories highlighted the turning points, inspiring a description of one's experience that was rich, deep and human for both the teller and listener. This teller-listener relationship is an important observation and was integral to my study.

The final study that warrants review is "*Traumatic injury and identity: Incorporating traumatic episodes into life story*" by Valvano (2012). Valvano (2012) concentrates on meaning-making following a traumatic event, improving our understanding of identity formation and narrative reconstruction post-SCI. There are many themes that arose from the life story interviewing, including adverse events, altruism, faith/religion, clarity, future as continuation of present and tone. She found that how people told their story often affected the resulting narrative. For example, stories filled with selflessness, faith and affirmation tended to be told by people with higher levels of wellness.

These findings were important for two reasons. First, they helped me understand how people who have experienced a forced identity transition can construct post-injury identity, despite what often feels like the unraveling of self. Narration allows for meaning creation as people reconstruct their experiences into meaningful narratives that are predictive of positive, post-SCI adjustment. Secondly, Valvano (2012) provides another perspective on resiliency in identity studies, a concept often associated with illness and injury narratives. Specifically, her idea of

resiliency is tied to pre-injury perception and the impact that would have on post-SCI identity (e.g., self as athlete and physical self).

### **Summary**

An initial review of theoretical literature on identity and narrative (Clandinin & Huber, In press; McAdams, 2011; Bamberg, 2004, 2010; Frank, 1995; Kramp, 2004) reveals common understandings as well as differences. First, the theoretical perspective from which the definitions of identity and narrative are derived appear to be similar. For example, many authors (Clandinin & Huber, 2010; McAdams, 2011; Bamberg, 2004, 2010; Frank, 1995; Pals, 2006; Lohne, 2007) apply post-positivist and interpretivist thinking, by opening a dialogue for discovering and unpacking the notion of multiple truths and narrative knowing, asking *why* instead of *how*, unpacking the individual and social aspects, along with the formation and transformation of identity. This way of thinking allows for both/and while paying particular attention to the contradictions of stable and fluid over time and at particular points in a person's life.

The differences tend to surface with regard to the utilization and application of these concepts. These differences are primarily grounded in how each author portrays the purpose and process of narrative creation and knowledge. In some cases (McAdams, 2011; Engle & Munger, 2007; Dunn & Burcaw, 2013; Valvano, 2012; Freeman, 2000) their understanding of the process of narrative creation is informed by cultural, social or structural processes, and the findings are interpreted as per that

ideological framework. For others (Frank, 1995; Pals, 2006; Bamberg, 2010), differences are based on why, how and to what end identity and narrative are utilized. For example, narratives can be in the form of life stories or used for identity creation and solidification. In other instances, narratives contribute to the understanding of identity and are used for purposes pertaining to adjustment and transition.

As per the review above, it appears that the bulk of the research on identity and narrative is broad and theoretical (Bamberg, 2004, 2010; McAdams, 2011; Freeman, 2000; Riessman, 2005). However, narrative research has been applied to various populations who have experienced a forced identity transitions (e.g. spinal cord injury) and difficult life events (i.e. illness). In contrast to the presented studies (Riessman, 1990; Yoshida, 1993; Sparkes & Smith, 2005; Valvano, 2012), many (Rosenstiel and Roth, 1981; Bach & McDaniel, 1993; Cairns and Baker, 1993) have used narrative research to *understand* quality of life, adjustment, employment, and living with a spinal cord injury, rather than to interpret meaning. For example, there have been numerous studies on spinal cord injury, but only a few have delved into the use or function of narrative in identity transitions associated with SCI (Lohne, 2007; Dunn & Burcaw, 2013; Valvano, 2012). In other studies (Sparkes & Smith, 2005; Dunn & Burcaw, 2013; Pals, 2006), the researchers developed conclusions based on phenomenological analysis (i.e. the “disability experience” in the presence of metaphor, time and hope) instead of meaning (i.e. what was the deep-rooted purpose of “the battle” metaphor for the participants), ultimately exploring the event (i.e. the rugby game) as oppose to

significance (i.e. what it meant to be an athlete while acknowledging the shift in physical self).

## CHAPTER THREE

### **A Story about Narrative Research: Methodology and Method**

*You begin and end with the storyteller - Mary Kramp (2004)*

#### **Rationale for Narrative Method**

Creswell (2007) suggests that qualitative research provides a detailed and comprehensive perspective on a particular event, phenomenon or experience in that it gives rise to a deeper sentiment when studying the lives of real people, places and experiences. Furthermore, qualitative approaches complement the profession of social work in both practice and research, by providing the opportunity to gain knowledge of an experience. This can be achieved through the collection of stories, reporting on individual experiences while discovering and ordering the meaning of such (Creswell, 2007; Larsson & Sjoblom, 2009).

Narrative research is a specific type of qualitative method. It is particularly suited to studies that have as their focus the stories told by research participants. The interviews are structured in such a way that the resulting data takes the form of and is understood as a collection of stories. The purpose of narrative analysis is to not consider the data as merely stories that transmit facts or *the truth* about the world, but rather as accounts that act as interpretive devices through which people represent themselves (Riley & Hawe, 2005). Riley and Hawe (2005) suggest that narrative methods "may give new and deeper insights into the complexities" (p. 227) of lived

experience. Narrative research allows for the privileging of participant perspectives while gaining a deeper understanding of lived experience through a defined research process. Therefore, the aim of narrative research is, as Riessman (1993) suggests, to discover “what life means at that moment of telling” (p. 52).

I have selected the qualitative method of narrative research for several reasons. First, many authors will agree that narrative research offers an in-depth understanding of lives lived (Larsson & Sjoblom, 2009; Riessman & Quinney, 2005; Josselson & Lieblich, 1999). It demands that the teller (i.e., the participant) be held in highest regard. Stories are respected and utilized for the primary purpose of *understanding the teller’s* experience, rather than the offering of the listener’s (i.e., the researcher’s) interpretation. Meaning is embedded in these narratives told by participants during the course of selective narration (i.e., the interview), as participants share what they deem necessary, important and significant in that moment, at that time (Josselson & Lieblich, 1999). The purpose of the interview is the social construction of stories, which are grounded in lived experience, and reflective of and informed by postmodernist notions of truth.

Second, as a method, narrative research can complement social work practice. It can be useful as a methodological tool for investigation and evaluation. Narrative is also used as a treatment method, incorporated into strategies that foster individual growth through sharing of stories (Larsson & Sjoblom, 2009). In this case, it can be

applied as a research method that evokes a certain level of first-person sharing not achievable with other methods.

Third, narrative research is well suited to the study of identity. According to Larsson and Sjoblom (2009), "telling a story is a way of telling someone else about the self, but also about the teller's identity constructions" (p. 274). In turn, these stories convey meaning about self as well as the contextual nature of the narrative being shared. The researcher becomes privy to knowledge that only the participant has access to. Ultimately, narrative research is a specialized method of researching identity and identity construction, forced or otherwise.

Fourth, narrative research is also exploratory, supporting concepts and practices that look below the surface, in hopes of gaining a deeper understanding of the individual, while being unassuming about contextual variables that may already exist (Larsson & Sjoblom, 2009). There is no preconceived notion as to what may or may not already exist, as is the case with quantitative methods. Rather, identity and forced identity transition are illustrated and understood via the narration. In addition, narrative approaches become an outlet for participants to express and even understand identity in the context of stories that reveal both the details and the meaning behind identity shifts over the course of one's life, especially following forced identity transitions (Larsson & Sjoblom, 2009; Riessman & Quinney, 2005; Josselson & Lieblich, 1999).

Lastly, given that narrative research is a qualitative method, it allows for less restrictive sampling, such as snowball, non-probability and purposive sampling, which presents the opportunity to gather rich and layered data from self-identified “experts.” I worried that it might be difficult to find participants who had not only experienced a forced identity transition, but were also spinal cord injured. That they had to be willing to share their experience as it pertained to identity and be residing in Nova Scotia compounded the problem. Given these inherent difficulties, the sampling methods intrinsic to qualitative research were conducive for this study.

### **The Gathering of Narratives - Design**

#### **The Narrative Interview**

Jovchelovitch and Bauer (2009) suggest that there is “no human experience that cannot be expressed in the form of a narrative” (p. 1). Narrative interviewing is a specific interviewing technique designed to elicit stories from the participant. Given that the aim of this study was to determine the effects of the SCI on identity narratives, it seemed only fitting to use an interview design that allowed for the telling of stories. While it can be difficult to apply in its entirety, I chose this specific interview design primarily for the attention it pays to the interviewee, the narrator. The interview was meant to stimulate stories about a significant event and the contextual aspects of that experience. The narrative interview became the reconstructive process of those events from the perspective of the participant (Jovchelovitch & Bauer, 2009). The narrative

interviewing method did not aim to elicit structural, character or philosophical details, but rather focused on the gathering of stories to discover meaning and purpose.

The interview guide (see Appendix H) was created in accordance with the narrative interviewing schema presented by Jovchelovitch and Bauer (2009) and Hunter (2010). I gathered information using broad interview questions, which were as unstructured as possible (within reason). The focus was on the participant telling the stories, with as little interruption as possible from me, the interviewer. This was a deliberate decision, mainly because I was very aware of my position and consequent power as a researcher. Prior to the interview, I chose to reflect on that power to ensure that the storyteller remained central to the process. For example, because I decided to use a narrative approach to interviewing, I sought to acknowledge both the political nature of my research and the powerful position I held as a researcher in relation to those participating, in this case those who volunteered to share intimate details of their experiences. Furthermore, reflexivity allowed for a greater self-awareness where I was my own subjective lens could be unpacked, especially as it related to researcher power, participant knowledge, notions of truth, co-collaboration, and assumptions about SCI, identity and narrative.

In the end, my approach was consistent with the literature, which suggests that the interview should be conducted with minimal influence of the interviewer, while still being mindful of the objective (Jovchelovitch & Bauer, 2009). As such, study participants used their own language and formulated their own narrative techniques,

in a structure that reflected a self-generating story. As Jovchelovitch and Bauer (2009) explain, the challenge of this method is working with what is given.

My narrative interviewing strategy followed the phases outlined by Hunter (2010). The first phase is *post preparation*, which is the formulation of the topic and the basic questions. This is followed by the second phase called *initiation*, which involves introducing the topic to the participant complemented by a visual document of some sort (e.g. an information sheet or informed consent statement). This is followed by phase three, *narration*, which refers to the participant telling his or her story with no interruptions from the researcher, only non-verbal encouragement to allow for continued story telling. In the next phase, *questioning* the interviewer can ask the participant simple follow-up questions (e.g. What then?). The interviewer must try to avoid asking why-questions and questions that reflect the interviewer's opinions or attitudes or suggest contradictions. This interview concludes with a period of time when the recording device is switched off. Other questions can be asked at this time and open discussion can ensue. Immediately following the interview, the interviewer is to write down, from memory what was said during this period. In some instances this type of interviewing works well, while in others the technique can leave gaps, as was the case with my study. The presence of narrative gaps will be addressed later in this chapter.

While there are many guidelines governing narrative interviewing, much is left to the discretion of the interviewer, such as the questions, the consent process, follow-

up, direction, and length of interview. This was indeed an ethical consideration as I tried to navigate the fine line between individually constructed stories and co-constructed stories, where my involvement had the potential to influence the narrative that was shared. Given that narrative interviewing can be adapted and changed to suit the topic of interest, I needed to be aware of the parameters of ethical narrative research, including the importance of reflexivity, to ensure that I was self-aware and conscious throughout the entire process.

### **The Collecting of Narratives - Collection Method**

The data for this study were collected using one, in-depth narrative interview of each participant, in accordance with the phases outlined above. The interviews focused on gathering information about the forced identity transition and the participant's identity before and after sustaining a spinal cord injury. Questions were related to self-understandings specific to three time periods: pre-injury, during rehabilitation and post injury. These questions were designed to assist the participants in recalling those experiences that may not have been at the forefront of their memories but were pertinent to the research. I asked clarifying questions on occasion, but maintained my role as an attentive narrative interviewer. During the post recording phase the focus was on random thoughts, experiences or statements that participants felt required further explanation and clarification. It was often a great time for open, unfiltered discussion, allowing for a particular freedom that the recording device may have stifled up to that point. Overall, the interview was an outlet, inviting participants

to share their story about each stage of transition, in a way that was meaningful for them.

Interviews ranged from 45 minutes to two hours in length. They were conducted in private settings, determined by the participants. Four interviews were conducted in my office at my place of employment in Halifax, Nova Scotia and two were conducted at the participants' homes. The interviews took place over a two month period and rescheduling was required on three occasions due to disability related health needs (e.g. skin issues, bladder infection, etc.).

Prior to each interview, initial contact was made either in person, via phone or email to introduce myself and to confirm eligibility requirements, participation and scheduling. The interview typically took place within one week of this initial conversation, except in one instance when the participant had to leave town for a family matter. This interview was scheduled for the following week. I transcribed, reflected on and made detailed notes on each interview, which each participant was given the opportunity to read if they so chose. One participant requested to read the transcript. Each participant was also offered the opportunity to forward any related thoughts or comments after the interview. I received comments from one participant via email and this document was added as an appendix to the interview transcript (or notes).

## **The Gathering of Narrators - Sampling Plan**

Participants were selected using purposive sampling techniques. According to Bernard (2006), "in purposive sampling, you decide the purpose you want informants (or communities) to serve, and you go out to find some" (p. 189). There is no sampling design per se "that tells you how many of each type of informant you need for a study. You take what you can get" (p. 190). Consequently, it is not enough to concede that because this was a qualitative study, purposive sampling was a given. Instead, this study required a critical case sample, which is sample made up of participants that are likely to yield the most information, and have the greatest contribution to and impact on findings (Bernard, 2006). In this study, the critical case sample was maintaining a specific focus on critical, life altering events that changed the course of one's life.

As with many qualitative researchers, my purpose was not to generalize my findings to a larger population but rather to unpack and understand a particular concept and circumstance in depth. In this study, I could draw on my knowledge of the population, given that I have worked with people with spinal cord injuries for over seven years. I understood the barriers to participation in research such as location, transportation and timing, and took this into consideration when choosing a sampling strategy. Also, this type of sampling fit the overall purpose of the study (Klein, 2011), which was to collect narratives from a specific group of people. Choosing participants based on the data they could provide ensured that they were able to speak to the topic at hand and had an interest in what was being studied. According to Bernard

(2006), "all samples represent *something*. The trick is to make them representative of what you want them to be. That's what turns a convenience sample into a purposive one" (p. 192). My sample strategy went beyond the mere convenience of access, taking into consideration a group of people that would indeed understand how a forced identity transition shifts and changes the narratives that follow.

I utilized a quasi-snowball technique to bolster the sample when the recruitment of participants through purposive sampling proved difficult. Like purposive sampling, snowball sampling is useful when studying "hard-to-find or hard-to-study populations" (Bernard, 2006, p. 192). According to Bernard (2006),

In the snowball technique, you use key informants and/or documents to locate one or two people in a population. Then, you ask those people to (1) list others in the population and (2) recommend someone from the list whom you might interview. You get handed from informant to informant and the sampling frame grows with each interview (p. 193).

Snowball sampling occurred on two occasions; once at the beginning of the recruitment phase, and once near the end of the interview phase when an interviewee recommended an individual for the study. Quasi-snowball sampling proved to be very useful for this particular study.

As for the actual sample selection, I tried to have as much variety as possible with respect to level of injury<sup>5</sup>, ability, and length of injury. I wanted variety for three reasons. Firstly, I wanted to evoke narratives that explored a range of identity

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<sup>5</sup> The phrase "level of injury" is both a medically and socially defined category. I am aware that the language is quite restrictive, however it is reflective of the language used by the participants and within peer groups. It is not intended to be a totalizing description.

transitions. I thought it would be important to represent all levels of injury because I could then gather identity narratives that took into account the nuances that would otherwise have been ignored. For example, the level of arm and hand function may not be noticeable when listening to a recorded interview, but it was pertinent to the details in the story itself and influenced the shape that narrative would take. Level of injury became a unique factor in the telling, authoring and shaping of each narrative and its connection to identity during each transition.

Secondly, while some experiences are similar, the resulting effects of the injury could be very different for each participant. By including individuals from each level of injury, both the unique circumstances and the commonalities could be recognized. Furthermore, I could not assume that one injury was equal to another by classification alone. Even though the injuries may be "similar," the family situations, educational backgrounds, support systems, abilities to adjust and adapt, and physical, medical, and psychological needs would be different for each participant given the influence of contextual factors.

Lastly, an emphasis on one sub-category would be limiting. Given that the purpose of the study was to explore the use of narratives and how they may be used to represent identity transition in persons with spinal cord injury, it seemed appropriate to have the multiple levels of injury classification represented in the sample. This decision was made in hopes of discovering deeper narratives related to identity transition in the broadest sense.

## Recruitment

Six participants were recruited, four with the assistance of a colleague who has a spinal cord injury and is very well connected to this community, and two from these participants using the snowball technique referred to earlier. I specifically sought out participants with stories to share about sustaining a spinal cord injury and their subsequent transition, as well as the ability to communicate those experiences in an interview setting. The telephone script for recruitment (see Appendix A) approved by the Interdisciplinary Committee on Ethics in Human Research, was used by my colleague to contact persons living with SCI in the province of Nova Scotia. During this process, my colleague maintained confidentiality with respect to whom he contacted. I was made aware of only those individuals who met the criteria and approved follow-up. My colleague was not aware of who ultimately agreed to be a part of the study.

I then contacted each individual to ensure that they met all the sample criteria. It was important to determine whether or not potential participants fully understood what was being asked of them and what they could expect (i.e. potential triggers, purpose, potential questions, etc.). After they ensured me that they did, I informed them about the interview structure, clarified the narrative method and described the nature of this research. At this time I also covered matters pertaining to confidentiality as well as the benefits and risks associated with this study. Before each interview the *Informed Consent Statement* (see Appendix D) was read with each participant, as was the *Verbal Debriefing Statement* (see Appendix E). Each individual was given time to

ask questions and seek clarification, after which they were expected to sign the *Informed Consent Statement* (see Appendix D) or offer verbal confirmation that they agreed to the terms, if they were unable to physically sign the document.

### **Sample Criteria**

The sample criteria were specific. First, the participants could not have been past or current clients of mine. This stipulation was put in place to avoid unintended bias, hindrance of participation, fear, breach of confidentiality, and/or situations arising from known contextual factors. Furthermore, for the purposes of transparency, building trust and engaging in ethical research, it was made clear that I was involved in a research capacity only and not as a social worker for the Canadian Paraplegic Association Nova Scotia (CPANS). Given my experience working with persons with spinal cord injuries, I was aware that I was approaching the research with some preconceived assumptions and that there was the possibility that these would interfere with the participant's ability to let their story unfold. I was also aware that the participants may have made assumptions about me and my level of knowledge and familiarity with SCI and as a result may not have felt the need to elaborate or fill in the gaps as much as they might have done with a researcher who did not have this knowledge.

Second, it was vital that all potential participants be made aware of the voluntary nature of their participation and that they were inactive clients, meaning they were not receiving services from CPANS at the time of the interview. This criterion was

put in place to ensure that participants did not feel that their decision to participate (or not) would affect their services from CPANS (directly, indirectly, adversely, etc.).

Given the sample specifications discussed above, each participant met the following criteria:

1. He or she had sustained a spinal cord injury and considered it to be a life altering experience;
2. He or she acknowledged that having a spinal cord injury altered his or her sense of self;
3. He or she experienced the SCI as a forced identity transition, in that he or she neither desired nor initiated the change;
4. He or she experienced the SCI as a momentous event that posed identity challenges;
5. The period of transition was still accessible and fresh in his or her memory yet sufficient time has elapsed such that he or she had an opportunity for reflection;
6. He or she had not received nor was currently receiving social work services from Lorna Griffin-Fillier (researcher).

### **Sample Size**

According to Alder and Alder (2012), “qualitative research methods differ from quantitative approaches in many important respects, not the least of which is the latter’s emphasis on numbers” (p. 8). Quantitative studies tend to capture “a shallow band of information from a wide swath of people and seek to objectively use their correlations to understand, predict, or influence what people do” (p. 8). Meanwhile qualitative studies involve fewer people, delve deeper into “those individuals, settings, subcultures, and scenes, hoping to generate a subjective understanding of how and

why people perceive, reflect...interpret, and interact" (p. 8). While size is not necessarily the primary objective, qualitative research does demand a richness of data that in some ways determines sample size.

Alder and Alder (2012) write, "a small number of cases or subjects" (p. 9) may be adequate, especially when studying "hard to access populations" (p. 9). In those situations, "between six and a dozen, may offer us insights" (p. 9) . While redundancy is often the goal, sometimes that cannot be achieved given the population being studied (Alder & Alder, 2012). However, when using such a small sample, some may be concerned with issues of representativeness, objectivity, validity and reliability, but these concerns are not necessarily relevant given the purpose of inductive research (Alder & Alder, 2012).

That said, I initially wanted to have a sample size of 10-12 participants. However, I ended up getting six, well informed and dedicated participants (five males and one female), representing four types of spinal cord injury, with various levels of injury. While many potential participants were interested, the time frame within which the interviews needed to be completed, health related issues related to the disability (e.g., skin breakdown, bladder infection, medications) were deterrents. In addition, some potential participants felt they could not participate because they did not fit the sample criteria. Also, given the time constraints of the MSW program, I was working with an interviewing period of three to four months, which narrowed the possibilities of participation even more.

## Analyzing Stories

### Selecting a Method of Narrative Analysis

There are many approaches to narrative analysis and methods of representing narrative data, such as: Creswell's (2007) chronological analysis, Labov (1982) structural narrative analysis, Riessman's (2008) dialogical/performance analysis and, Kramp (2004) and Trahar's (2009) approach that draws on Polkinghorne's (1995) analysis of narratives. All are applicable in their own right depending on the purpose of the research. For example, Creswell (2007) states that "the data collected in narrative study needs to be analyzed for the story they have to tell, a chronology of unfolding events, and turning points or epiphanies" (p. 155). While knowing the order of unfolding events is important in some circumstances, I was more interested in unpacking the meaning, and was therefore inclined to draw on Riessman's (2003) approach to analysis.

There are many challenges associated with narrative research, including issues pertaining to validity as well as appropriate and accurate analysis and representation of the stories shared. As suggested by Clandinin and Connolly (2001), the notion of story as representation of a construct versus facts can indeed come into question. Are the stories analyzed as constructs of experiences or are they to be understood as truth? The answer to this question ultimately influences the analytical approach. Given that narrative analysis is often influenced by the individual researcher, the approach to analysis is almost as individualized as the stories themselves (Hunter, 2010). While

there are similarities in approach, they are not void nor unaffected by personal ideological or theoretical stance.

My method of narrative analysis was concerned first and foremost with unpacking meaning in the narratives shared and thus going beyond explaining and describing specific events, details and happenings present in each story. The intention was to discern common elements, themes and meaning creation offered by the narrators themselves. I then combined Riessman's (2003) dialogical/performance analysis with the approach outlined by Hunter (2010), which provides the researcher with the opportunity "to go beyond the search for one grand narrative and examine the transformative process of storytelling" (p. 47). This approach to analysis reflects the notion that stories are rich, layered accounts of personal experience and communicated on a level beyond statistical operations, which provide only part of the picture for the researcher. The stories "are deconstructed to reveal powerful discourses, hierarchies, presuppositions, deliberate omissions and polar opposites" (Hunter, 2010, p. 47).

Specifically, I utilized Riessman's (2003) thematic analysis where emphasis is placed on context - *what* is said more so than *how*. The language itself became an outlet for meaning creation with common themes identified across each interview. When I attempted to create a thematic matrix of sorts, it became complex and interwoven, and meaning appeared to be lost in the simplistic representation that filled my whiteboard. While it was an effective way to bring together common threads

as well as individual differences, it did not allow for the subtleties found in the gaps (i.e. periods of no speaking, abrupt ending, and statements followed by long pauses). This meant that I needed to dig deeper. So, I began isolating mini-narratives based on identifiable opening and closing statements (i.e. "Well I grew up in...", "That's it", and "There was this one time . . .") (Riessman, 2003) and incorporated those mini-narratives with Hunter's (2010) analytical strategy.

Incorporating aspects of Hunter's (2010) layered analysis meant that I could begin coding the mini-narratives under the categories of pre-SCI, during rehabilitation and post-SCI, allowing the broad interview questions to influence *grand* categories. From there, sub-themes (topics) and deeper meanings (the point or purpose of the story) emerged and I referred back to my notes and the transcripts to confirm accurate representation. As Riley and Hawe (2005) suggest, "the researcher looks for patterns in the data, labels them and groups them accordingly" (p. 229). I then continued to unpack content (e.g., what was being shared), how it was told (e.g., pauses), and the meaning highlighted by the narrator (e.g., one participant referred to his "vanilla life").

After these steps were completed, I re-read each interview again, between 4-6 times, listening first for grand narratives, then for mini narratives, individual voice, obvious changes in identity and shifts that occurred, trying tirelessly to draw out both the similarities and differences between each narrative through a comparative analysis. I then grouped the narratives based on core content in relation to identity transition and sense of self. As Larrsson and Sjoblom (2009) suggest, it was important to

understand and highlight the moments when “identity constructions or identity switches” (p. 274) occurred in various situations. The constructions or switches were incorporated into the categories of pre-SCI, during rehabilitation and post-SCI, as described above.

During the final stage, overarching narratives that were transformative began to surface (e.g., Family Narratives, Rehabilitation Narratives, Reasoning Narratives, etc.) and I used those as a foundation for analysis. Overarching narratives “express a change in how the storyteller evaluates something, such as an epiphany (Riley & Hawe, 2005, p. 230). Next, I sought out narrator interpretations (Larsson & Sjoblom, 2009). These were the moments when the tellers looked back on the transition and constructed a mini narrative that explained their understandings of themselves in that moment at that time (e.g. Explanation Narrative). These mini-narratives were rife with meaning and used to understand individual constructs as related to shifts in identity.

### **Presenting the Findings**

The challenge then became how to present the findings, a test for many narrative researchers (Hunter, 2010). How could the participants’ voices remain present? How could each narrative (grand and mini) be represented? As stated by Connelly and Clandinin (1990), part of the difficulty was “to understand and portray the complexity of the ongoing stories being told and retold in inquiry” (p. 9), while ensuring that as narrative researchers we “move beyond the telling of the lived story to tell the research story” (Riessman, 2005, p. 10). My role was not simply retelling but

rather interpreting narratives, establishing connections and unpacking meaning (Riessman, 2005). For the teller, “truths of narrative accounts are not in their faithful representation of a past world, but in the shifting connections they forge among past, present and future” (p. 6), essentially reimagining lives. Consequently, it was my duty to assist in the forging of those shifting connections, bridging narratives between past self and current self.

In conjunction with presenting the findings, I decided that it was important for each individual to be truly represented. As such, each participant was represented by a brief narrative (see Chapter 4) in an attempt to make them come alive, showing the person behind the story rather than representing them as merely statistical data. To accomplish this, I used the teller’s voice. I identified each participant with a pseudonym when referencing their words, so the reader would recognize these as stories of real people. For example, I chose Taylor for the participant who felt his life was somehow pre-determined prior to injury and then within his control post injury. I used the name Destiny for the woman who kept referring to the accident as an act of fate.

### **Proving the Quality of Stories - Methodological Issues in Narrative Research**

Qualitative research methods are rooted in the interpretivist paradigm and are understood to be flexible and contextually sensitive and are used to understand complex issues (Carcary, 2009). This type of research is inherently subjective, as we use words instead of numbers to grasp the diversity of experience. As such, it is not

appropriate to apply "scientific" or traditional notions of validity, objectivity and reliability to narrative research. It is, however, essential to redefine these standards of rigour, keeping in mind that the purpose of narrative research is to study personal experience and meaning in a systematic manner (Carcary, 2009; Giovannoli, 2013).

In narrative research there is no attempt to generalize or adhere to laws that suggest consistency in replication. Instead, Polkinghorne (1988) suggests that the presentation of narrative findings needs to be "retrodictive" (the act of making a prediction about the past), rather than "predictive" (p. 171). Findings need to be used to build a reasonable and believable account so that "their parts in the whole story become clear" (p. 171). This offers *validity* but not in the scientific sense. What then are the standards of rigour for narrative research? Carcary (2009), Lieblich et al. (1998), Riessman (1993) all propose a framework for the evaluation of narrative studies, by which this study will be examined - width, coherence, insightfulness and parsimony. I deem this to be sufficient.

### **Width**

According to Giovannoli (2013), width "refers to the amount of evidence that is provided to allow the reader to make an informed judgement on the evidence and its interpretation" (p. 42). Width is similar to Riessman's (1993) notion of *persuasiveness*, with the added layer of plausibility (reason). In this study I collected, provided and analyzed significant narrative data in such a way as to inform the reader. I allowed the participants to view the transcripts. I asked them if there was anything else they would

like to add to ensure depth and accuracy. I also compared my research findings to similar studies at this level (Scott, 1997; Dorsett, 2001; Pedro, 2010) and concluded that the amount of data collected and analyzed was indeed sufficient to reach the conclusions that I did. Lastly, I included an entire chapter with biographical information and overall narrative disclosure for each participant, which adhered to the criterion of width by being layered in description and deliberate in technique.

### **Coherence**

Coherence refers to how the findings fit together and how they compare to previous research and theory (Lieblich et al., 1998; Giovannoli, 2013). Coherence can be achieved via *consensual validation* (Lieblich et al., 1998; Riessman, 1993), a process that involves sharing one's "views and conclusions" (p. 173) and ensuring that these make "sense for researchers and informed individuals" (p. 173). To insure that coherence was achieved, I consulted with several different sources throughout the process: my thesis supervisor, colleagues, the research participants and the literature. Dr. Catherine de Boer and I discussed the transcripts on several occasions and at great length, sharing our thoughts and ideas throughout each phase of the study. I also provided two colleagues with a summary of my analysis and they provided me with an alternate perspective and asked questions that I had not have considered. I also referred to several narrative studies and authorities on the narrative research (Riessman, 1993, 2002, 2005; Bamberg, 2004, 2010; Lohne, 2007; Clandinin & Huber, 2010; Freeman, 2000; Kramp, 2004; Lieblich et al., 1998) to ensure I was following the

analytical processes deemed appropriate. Lastly, I informally discussed my thoughts with five of the participants to ensure clarity and accuracy which is an important ethical consideration.

### **Insightfulness**

Insightfulness is directly linked to the reader. Does the research give the reader deeper insight into their own life (Lieblich et al., 1998; Giovannoli, 2013)? While I would hope that my research provides insight, this study is much like the narratives collected - individualized, subjective and applicable to that moment in time. I am confident that this research will provide immeasurable insight into the lives of the people I interviewed and we can all relate to the idea of transition, given that we all encounter it at some point in our lives. This study allows readers to suspend their own reality, even for a moment, as they connect to six other individuals on a personal and vulnerable level.

### **Parsimony**

Parsimony refers to the “literary merits” of the overall presentation of the story and one’s ability to provide analysis based on a small number of concepts that are appealing (Lieblich et al., 1998). Parsimony can be linked to “pragmatic use” as presented by Riessman (1993), which refers to whether or not the research lends itself to future exploration or further research. The thought and time put into the presentation of these stories was done with the utmost care and respect for the teller. That, combined with my passion for narrative research conveyed in this study could

certainly spark an interest in those who may not have attempted narrative or identity studies in the past. I wanted to make this study accessible to everyone - academics, learners and “experts” alike.

Given that this study is not exhaustive, it most certainly lends itself to future studies and there is still much to learn about forced identity transitions and identity narratives beyond spinal cord injury. Narrative is more than simply telling stories. Narration is a way for us all to create and recreate our realities and ourselves. That is the unique contribution of narrative research.

### **A Note on Reliability**

In the case of narrative research, reliability refers to the dependability of the data and the incorporation of procedures that insure that the data collected during the initial stages (interviews) are properly and fairly represented (Lieblich et al., 1998). This is necessary in narrative work (Riessman, 1993). However, the notion of dependability or truthfulness requires special attention. The idea of truth is profoundly influenced by theoretical perspective. In this study, *the narrative* was considered *truth* given that it is a construction of reality. Despite what may be missing, intentionally omitted or forgotten, misrepresented or otherwise, the participant is still revealing *truths*. This study was not concerned with debating actuality but rather, with presenting and interpreting the truths of one’s lived experience that only he or she can attest to. The challenge for the researcher was to discern context and level of subjective meaning

given that the aim is not to control or predict. Instead, the challenge was representing the stories appropriately by drawing on the voice of the storyteller.

Dependability also refers to replication where the aim is to reproduce the study using a different sample in the hopes of achieving similar results (Carcary, 2009). In some cases, comparison studies can be utilized and implemented, but this was not an option for this particular study given the time constraints and program requirements. However, measures were taken to bolster dependability, beyond the confines of reliability and replication. The data in the form of transcripts, void of my interpretation, were forwarded to my thesis supervisor for comments and considerations. She gave me feedback about the interviews, the questions asked, the obvious gaps in the stories, and my influence as the audience (i.e., my knowledge of spinal cord injury that may have contributed to these gaps). This feedback was followed by a discussion of our findings. We concluded that our thoughts regarding preliminary observations were similar, thus supporting the dependability of the process

### **The Shortcomings of Gathering Stories**

#### **Shortcomings of Narrative Research**

The limitations of narrative research vary depending on the group and topic being studied. Given the self-governing framework to this approach, issues may arise with collection, analysis and telling due to misunderstandings, self-inflections and personal interjections of the researcher. The gathering, analyzing and presenting of stories is a lengthy process that demands attention to detail on every level.

I have found little agreement in the literature about what exactly does or does not constitute a *narrative*. In some instances, researchers become storytellers rather than story analysts and the goals of narrative research become therapeutic and not analytic (Trahar, 2009). Others approach narrative research as a form of therapy. While I have utilized narrative counselling with clients in the past, my therapeutic ideations did not interfere or influence the analytical process and value of the research itself. I was quite aware of the difference between therapy and research, being sure to partition one from the other. My goal was not to illicit change as is common in therapeutic interventions, rather it was to listen for stories in hopes of building research knowledge. It was ensuring that the participants had ownership of their stories while trying to minimize the effects of my role. I conducted months of preliminary research on narrative methods before embarking on this study, ensuring that I was confident in its demands and was able to deem it to be the most appropriate method.

Lastly, narrative research can rely heavily on the researcher's interpretation where they re-present narratives as if they were authentic (Trahar, 2009; Labov, 1997; Riessman, 2007). Many argue such stories are not *the* truth but rather experiential truths constructed through forms of narrative. This misrepresentation can occur if the researcher is merely reproducing the story heard, as opposed to offering a critical examination of what was told. Furthermore, the story becomes subject to personal response and this is the fundamental reason why the narrative researcher has a

responsibility to seek out supporting evidence and arguments for the claim that is made (Trahar, 2009).

### **Potential Restrictions of This Study**

First, this study did not attempt to generalize the identity experiences of the participants to all persons living with spinal cord injury or to those who have experienced a forced identity transition. Nor did it imply that narratives are the only way to reflect on and explore identity transformation and creation. Instead it presented one possible method for understanding the effects of such an event on the narratives and experiences of six individuals. While the findings cannot be generalized, they do contribute to the body of knowledge on identity, narrative and the creation of narrative self (Bamberg, 2010; Kramp, 2004; Clandinin & Huber, 2010; Riessman, 2002, 2005). Furthermore, this study did not attempt to reach finite conclusions, but rather it endeavoured to understand the experiences of others through the narratives they shared in the hopes that the findings may provide insights and avenues for future work with persons experiencing transition. This study was merely another attempt at learning through lived experience and storied lives.

Second, while measures were taken to prevent unconscious bias, the reality is, objectivity (in the modernist sense) cannot be achieved in qualitative research, especially studies rooted in postmodern and social constructionist perspectives. The questions themselves, to a certain extent, represented what I wanted to know, as

opposed to what the participants might have wanted to tell me. While I attempted to be as “objective” as possible, it would be more appropriate to say that I was fair, inclusive, equitable, just and forthcoming during the research process. Also, as with all narratives, they are only true for that person at that time. As one participant remarked, “If you were to ask me the same question tomorrow, my answer would probably be different.”

Third, it is important to highlight the influence of position and perceived knowledge. In this study, my position as a social worker may have affected what was shared during the narrative process. While I have never directly counselled any of the participants, they seemed to assume, given my employment history, that I had a particular level of knowledge of and experience with persons with SCI. This became evident to me during the analysis process in two ways. First, there appeared to be gaps in the amount of detail shared, specifically details that pertained directly to living with a spinal cord injury. Secondly, participants chose not to elaborate on some experiences, where in other situations (i.e. with a different researcher) they may have. Granted this may be speculation, but nonetheless it was an observation and warranted transparency.

In the same vein, as a result of my experience, I did not follow up during the questioning process (refer to narrative collection in Chapter 3) in the same manner as another researcher probably would have. In some instances, this resulted in narratives that appeared incomplete. Consequently, under different circumstances, the tellers

may have chosen to elaborate more. The relationship between the teller and the audience/listener is indeed a collaborative and intricate one, in that the audience *is a part* of the telling. In this case, I unconsciously played a role in the telling and reconstruction of their narratives. Nevertheless, it did not seem to affect the outcome or the richness of the narratives shared. For example, because I was aware of my biases and assumptions, I was able to keep my involvement and influence to a minimum, choosing to allow their voice to take precedent. In the end, the stories are indeed their stories.

Last, given the time constraints governing this study, primarily due to program restrictions and parameters, saturation was not possible. The entire process, from ethics approval to final submission allowed me less than a year. The interviews began as soon as possible (September 2013), immediately following ICEHR approval (August 2013). If I had the opportunity, I would have interviewed at least 4-6 more participants to bolster the saturation argument in this study.

### **Summary**

This study used qualitative research, specifically narrative research. The study was grounded in a social constructionist and post modernist theoretical perspective and focused on the identity narratives of six individuals with spinal cord injuries. Stories were collected through narrative interviews, where ethical guidelines were followed (i.e. informed consent, withdrawal, and confidentiality). The stories shared were analyzed using a combination of approaches from Riessman (2003) and Hunter

(2010). The overall methodology was centred around the storyteller, paying homage to the stories shared and the people who shared them.

This chapter also touches on the ethical considerations in narrative research. Narrative research is based on subjectivity, and because of this, it requires a level of reflexivity not found in other forms of research. It requires the ability to transcend self-awareness and self-consciousness in an attempt to unpack the role of the participants, the production of knowledge, and the social locations and spaces that inform the building of that knowledge. It is not being afraid to deal with the uncertainties and discomfort associated with ownership, confidentiality, anonymity and mutually informed consent. It requires a deep understanding of harm assessment and the potential risks of sharing stories that may trigger difficult emotions. It requires the researcher to renegotiate the assertions found in the interview relationship, addressing inequalities and the presence of control. Narrative research is the epitome of person-centred research, which means it comes with very serious ethical concerns that demand negotiation, reflection and respect.

## CHAPTER FOUR

### The Storytellers

*Narrative privileges the storyteller. - Kramp (2004)*

#### Introducing the Narrators

Before attempting to unpack the findings and delve strategically into the presentation of analysis, it is important to introduce the narrators; the storytellers. In keeping with the tenets of narrative research, the storyteller must be considered during each step of the process. As Kramp (2004) so aptly stated,

the subject of [narrative] research is not the object of observation but is the narrator, the storyteller. Consequently, narrative [research] reconfigures the relationship between the interviewer and interviewee that is characteristic of traditional research. You as a researcher give authority to the storyteller, whom you acknowledge as the one who knows and tells (p. 111).

As such, it would be a disservice to share stories of identity and transformation without first introducing the narrators. In this chapter I will present the demographic information that seems most pertinent to understanding the narratives. Later in this chapter, I will also introduce the storytellers and their stories, offering a brief synopsis of each as a way of acknowledging “the one who both knows and tells.”

#### A Demographic Narrative of The Storyteller

The following areas are included in the demographic narrative: level of injury, education and employment, marital status and family, age-onset and current age and gender. I chose not to include race and class (family and individual) in the demographic narrative for two reasons. First, it was a convenience sample and as it

happened, I had six people who self-identified as being white and there were similarities in social class. Second, due to the similarities noted above, I could not determine if race and class were indeed factors and therefore, I did not have enough range to pull out a varied analysis. That said, the race and class of this group was not an accurate reflection of persons with SCI. We know that SCI can affect anyone despite race, class, age, gender, marital status and so on. Furthermore, we know that finances are affected and have an effect on persons post-SCI. In the end, I did not have grounds on which to include this demographic information.

### **Level of Injury**

The participants in this study sustained injuries ranging from high level quadriplegia, meaning they had no use of their legs and minimal to no use of their arms and hands, to low level paraplegia, meaning they had full function of their upper body with no use of their legs. The level of function depended on whether the injury was complete or incomplete, meaning a complete spinal sever or incomplete spinal injury as the result of compression, tumour, trauma, etc. The lowest level injury was L1-L2, incomplete, meaning they had complete function from their lumbar or waist up. Another participant sustained a T12 complete, meaning they sustained an injury in the thoracic region and could feel/function from the chest up. The remaining four participants sustained injuries ranging from C4-C7, in the cervical region meaning they had varied levels of hand and arm function. There were two C4-C5 injuries, one incomplete and the other complete. The final two participants ranged from C6 to C7.

These distinctions are important because level of injury could affect how one adjusts and transitions. For example, it could have a tremendous effect on physical self understandings and identity construction post injury. It is also important to mention that while medically the injury classifications may be similar, how the injury was experienced varies, as does every story. This information is meant to provide a snapshot of the *medical* aspect of what each individual lived with, since the level of injury did have an effect on the stories that followed.

### **Education and Employment**

For some participants their educational background played a vital role in identity formation and transformation while for others education had very little bearing on the course of their lives pre and post injury. Four of the six participants completed post-secondary education, with one of the four completing graduate studies. Of the four who completed post secondary education, two completed their studies post-SCI, and these experiences were intertwined with their stories of both struggle and triumph. The remaining two participants completed their education at grade 12 and the other at grade 11. In both cases, education was not mentioned as a central turning point or as having great significance in the course of events.

With regard to employment, only two were employed at the time of the interview. One individual, an elite athlete, and the other, a paid consultant, retained their employment post-SCI. Three individuals participated in unpaid activities such as volunteering and duties based in the home and one individual was retired. Four of the

individuals worked for a period of time post-SCI but two left their positions due to health issues related to the disability; one left by taking early retirement.

### **Marital Status and Family**

All of the stories included some element of family, either related to parents, children or (ex)spouses. As such, highlighting this particular demographic information is important. Two participants never married, yet their parents and siblings were present in their rehabilitation and post-injury narratives. Three participants were divorced and one was married. Out of the three that were divorced, two experienced separation post injury. As for children, four of the participants were parents and there was a total of seven children. Two individuals had children before injury and two had children after injury. Discussions and experiences about children appeared several times in various narrative types at all three stages.

### **Age-Onset and Current Age**

Three of the six participants were injured in their 20's; two at 22 and one at 24. The remaining three individuals were injured when they were 18, 30, and 62. Age at onset was a significant factor considering many had lived with a SCI just as long or longer than they had lived without it. This undoubtedly had a considerable impact on their narration of transition and identity, which will be discussed further in Chapter Five.

The age of the participants at the time of interview ranged from 41 to 63. Three were in their 40's (41, 43, 49), one was 52 and the remaining two participants were 61

and 63. The length of time between age of injury and current age was substantial in some cases. While the average length of time one had a spinal cord injury was 21.8 years, the most common for length of injury was 19 years (three participants). The remaining individuals were injured for 1, 30 and 43 years.

## **Gender**

The sample of participants consisted of five males and one female. This is similar to the ratio of SCI related injuries in North American which is 4:1 male/female (CPANS, 2013). While the ratio has remained consistent for several years, the rate of SCI injury with women has increased slightly since 2004 (>0.1%) (CPANS, 2013). Men are still at a higher risk of injury due to sports related incidents, falls, motor vehicle crashes, and risk-taking activities (CPANS, 2013).

## **Synoptic Narratives of the Storytellers**

### **Tailor**

Tailor's story began with, *"I'm not like a big, gushing of details kinda guy... well I shouldn't say that. I could end up on tangents,"* a statement that reflected his calculated yet energetic and friendly demeanour. While I am sure he had many stories to tell, he was not entirely convinced of their importance or that he would tell them in the *"right way."* He was an active, energetic guy that fed on excitement and intrigue, which was evident in his reflections on sport. He described himself as a free spirit, travelling to find the next adventure.

Taylor was not one to speak endlessly about himself. He spent very little time talking about himself pre-injury and instead transitioned seamlessly to *"the moment,"* accompanied by threads of events that led up to the injury. He shared how he finished university before injury with little intention of settling down right away. He wanted to go and explore Canada, go skiing and live with friends who also craved something more out of life. He had just graduated from university and was seeking new experiences, and within a week of the move *"it"* happened. The *"accident"*. At that point in telling the story, he paused and said *"that doesn't really tell you who I was as a person though..."*

Taylor then began to reflect on life. Family. Kids. Marriage. At one point he *"kinda thought this was [his] destiny."* Family and career, combined with skiing would become his life. *"That was that."* While his choices pre-injury made his family happy, it was not *"anything that was going to be extraordinary."* It was a *"plain vanilla lifestyle."* However, *"destiny"* had a different plan especially after *"this thing"* happened. This was the moment when Taylor's life changed and he found himself thrust into a life that was both familiar and unfamiliar. He saw the *"old self"* in the midst of the chaos and remained grounded in aspects of self that were still there. He persevered, continued down a path that was no longer defined, embraced the *"crests and waves"* that come along.

Taylor referred to the injury as a *"rebirth."* *"It was his second life."* He told stories that defined and reflected those second chances, opportunities to do things

differently, moments not taken for granted and times when *"experiences were just better."* He was no longer living a life that was predetermined, and while he will *"never be a forest ranger,"* he will still live a life filled with adventure.

## **Marcus**

Marcus' narrative was grounded in an array of experiences. He travelled the world as an international consultant, eager to move on to the next challenge, chapter and experience. For Marcus, life was *"unassuming,"* yet the average person might have considered it adventurous. The *"moment"* for him was abrupt, stemming from an underlying health condition that required surgery. When he awoke, he *"was paralyzed."* *"It happened like that [snap] overnight."* However, he attributed his *"quick transition"* to his *"positive attitude"* and optimistic outlook. After all, for Marcus, the fact that he lived was *"a bonus."*

Marcus' story did not involve overwhelming moments of grief, loss or injury. Rather he moved effortlessly into stories that were centred on him helping others while in rehab and his plan to return to his job when he regained function. The only time he mentioned the injury was indirectly, saying *"my goal is to be up and out of this chair by April of next year."* While he did not consider himself to be the same as he was before the paralysis, he had not entirely *"moved on."* His pre-injury narratives were still very much intact as he recalled his education and employment background, yet he interjected with *"my job now is really looking after myself."*

For Marcus, the injury was a *"combination of abrupt transition and something [he] had to deal with."* While the injury may have been *"imposed"* on him, he believed that there was a reason for it. It challenged him to remain active and engaged rather than *"sit home and feel sorry for yourself."* He used that energy to help others as they adjusted and adapted to their situations. He still had something to offer. Yet he recognized that something was different for him *"because [he] got to live a life"* before injury and many do not, especially when they are injured young.

Marcus did not see this forced transition as a negative, but rather as a positive. Before the injury his work was his life, and his life *"was completely out of balance"* and *"well, it's back in balance now."* The injury became *"a corrective action."* He was coming to terms with a life that cannot be controlled, but *"accepted."* He often reflected on all the things he had accomplished and the life he had already lived, and even *"if [he] did not survive the surgery, [he] would have been happy with [his] life."*

## **Nigel**

Nigel's story explored his childhood, love of school politics and dancing in fascinating detail. He even ran for school president at one point, but unfortunately he lost. He was so *"devastated"* that he swore off *"public office after that."* He was not an athlete, like his sister. He was *"sort of"* an academic. He was involved in the comings and goings of his school, and recalled the *"good experience"* and learning opportunities. He was a B student and did not feel it necessary to apply himself, since further education was of *"vague interest."*

Nigel's life was also filled with excitement. Road trips with his friends that led to places that ended in *"wonderful adventure."* He continued to travel to quench the insatiable thirst for travel, which he had *"before [his] accident."* Nigel regretted not trying harder at school. He regretted not thinking about his future. *"It wasn't really a big deal which in hindsight angers [him] because no one told [him] about all the potential that was out there."* And while he classified this particular narrative as a *"projection,"* he believed that *"kids need mentors"* to help them succeed.

It was winter when Nigel was injured. He recalled trekking to an obscure place in the forest to go sledding with a *"friend."* While narrating events from that particular day, he glided unconsciously into a narrative that described his love of dance and the fact that he was a great dancer, only to return to *"the toboggan."* They were sledding when everything changed and he *"knew exactly what happened."* As his friend went for help, he was left alone. Cold. Scared. *"In screaming pain and stuff,"* which became too difficult to recount.

For Nigel, recovery, rehab and transition were not welcomed. *"It was just awful."* He *"hated it."* Consequently, he worked tirelessly to quickly meet the goals assigned, resulting in an early discharge from rehab. He simply wanted to be home, despite the fact that he knew *"life has changed."* He completed school because that *"became [his] only option."* It became about proving teachers, friends, and family wrong. He was determined to succeed at any cost.

Nigel's post narrative read like a historical account of a life well-lived. He recalled challenging himself to do better, to be better. Ironically, he furthered his education and settled into a career in politics. His job was demanding and began affecting his health. Nigel lived daily with reoccurring, debilitating pain. Eventually it became unbearable, *"absolutely out of control"* and he decided to retire. The pain lingered even as other areas of his life continued to shift and change. He described *"aging with a spinal cord injury"* and as he faced the complications that accompany the shift, he said, *"I've been in a chair so long, it doesn't mean that much to me." "It's engrained in who I am; it doesn't separate out. It's just a part of me. It has to be."*

### **Hunter**

As a storyteller, Hunter was less concerned with what was and more with what is. He focused very little on his life before injury and instead invested his words in describing the time during injury and after. For example, he briefly recalled experiences of hunting, fishing and engaging in outdoor activities and how he loved the nature and rural living. These experiences were important to him and was also a way to spend time with his family, especially his siblings.

Hunter then shared details of the experiences and events surrounding the injury. After *"hitting the water the wrong way,"* he remembered not being able to move. He recalled the how, where and when with little hesitation and said, *"It still didn't click in."* Hunter did not realize the extent of the injury until he arrived at the rehabilitation centre. That's when he was told *"[he] was never going to move again."* Yet despite the

shocking prognosis, he looked back on his time at rehab with fond memories. He reminisced about the friends he made and the people he met, and spoke of the drive that still keeps him going. He recalled becoming depressed at one point, vowing *"never to let it happen again."* He needed to keep himself occupied and became heavily involved in peer work.

Hunter became a peer, someone who could offer a *"been there"* approach to living with a spinal cord injury. *"I started coming to patients that were coming in and I've been doing that now for 17 years."* That was his motivation and it helped him deal with what is. This story served as a reminder of the gifts he still had and a sense of purpose despite the injury. It had become his *raison d'être*, not to mention *"it just makes you feel good."*

As Hunter reverted back to a narrative that described his time in rehab, he said, *"the hardest part was my kids were only young when I broke my neck and knowing that I couldn't pick them up no more..."* His children were and continue to be an integral part of his life. They too became a reason for living. However, Hunter's parents rarely came to visit and he would often ask why, but quickly added *"they never really did spend a lot of time with me."* They had *"battles of their own"* which were only exacerbated by the stress and unfamiliarity of this event.

### **Jeremiah**

Jeremiah's story began with an ode to his parents. *"They were good parents, I had a great childhood you know."* He spoke very little of himself and instead provided

story after story about his family. Even as he recalled being an athlete in hockey and baseball, he managed to intertwine narrative snippets of his family's contribution and dedication. He spoke at length about his siblings and their relationships saying *"they were great. We had no problems."*

As Jeremiah's story continued, he shared *"the moment"* when everything changed. *"I couldn't believe it happened."* His narrative became filled with struggle, challenge, perseverance, and strength. In talking of the great of odds he faced his story bounced back and forth between pre-injury, rehabilitation and post injury, as minute details surfaced that triggered break-away narratives, which took us to other places. He said, *"I knew medicine would never happen"* as he recalls the realization that he would never be a physician. He weaved in and out of narratives about family, friends, rehab, school, work and back to family, school, and on went the cycle. Jeremiah's narration was never about order, but rather drew on feelings, sharing experiences that obviously meant something to him, in that moment at that time.

Jeremiah recalled the struggle with juggling work and self-care, ensuring he fed his educational and career passions, while paying attention to and taking care of his body. His stories were always experiences of give and take, choices that had to be made even though they were difficult. Nevertheless, Jeremiah still shared stories of friendship that triumphed over disparity. He recalled his friends coming to see him in rehab and the friends he made while being there, relationships that had remained consistent. He shared stories of the peer work he engaged in, such as visiting others

*"who don't have a lot of people they can talk to." "As long as I can get out, that's the main thing."* He shared how he satisfied his love for sport and recreation, while still acknowledging that after the injury *"I really missed sports."* Jeremiah's narratives may have appeared chaotic, but to him they made perfect sense.

## **Destiny**

Destiny told a story filled with foreshadowing and *"fate,"* mixed with real experiences of challenge and accomplishment. She did not share a great deal about her *"nothing special"* life before injury. She said, *"It's been so long. I don't remember."* It seemed as if she no longer connected with that part of her life. The result was a story of a pre-injury self that was summarized in six brief, yet revealing, sentences. When asked about the injury she shared endless stories of what that was like, as she recalled the day it happened. *"[I] did not jump high enough out of the way,"* as if getting hit by a car was something she could have avoided or controlled. She recalled the date, day of the week, time, what she was wearing, what she said. It was solidified in memory.

When the topic of rehab was mentioned, Destiny recalled how she *"loved it,"* despite being homesick. Her stories of rehab were filled with friendship, awareness and compassion, verbalized in detailed conversations about people *"like me"*. In contrast, Destiny also spoke of lawyers, payments and a reality of not standing again. She recalled thinking that she *"couldn't live that long"* with a spinal cord injury. *"Sometimes you look at the bad."* Her story continued with narrations of life lived with a spinal cord injury and the things people take for granted, like a kitchen where the

dishes can be stored above and not below. For her the spinal cord injury became *"normal,"* something to which *"you just adapt."*

Destiny's identity as a mother was marked in memory. *"For moms, you know, it's different. You just do it."* For her, raising two children from a chair was *"all [she'd] known."* She shared that she loved being pregnant because she was healthy and looked after herself; being pregnant gave her a sense of purpose. Although, to her, being pregnant with a spinal cord injury was nothing special. She assumed it was the same as any other pregnancy.

Destiny often made a point to say she was *"the same person. Just sitting down,"* yet in the same breath admitting that things were very different. Her idea of disability was not defined by can and cannot, rather it was defined by movement and ability, how she defines herself and the effects the injury had on her and her family. She remarked that she appreciated the things *"walkers don't think about,"* the things *"they take for granted,"* like the first time you stroll on the beach with your 24 year old daughter.

In Destiny's world fate and foreshowing played a role in her individual circumstance. She described moments when what she said in passing, had come true. The accident. The payment. The t-shirt. The mimicked transfer. She turned each around *"so that there is a reason behind it,"* believing wholeheartedly *"things just happen for a reason."* For Destiny, justification served as a *"coping skill."* In the end she said, *"I lived it the best I knew how."*

## Summary

I used this chapter as an opportunity to introduce the narrators; the storytellers. As with all narrative research, the storyteller is a vital component of the process. The purpose was to connect the reader to the research through the participants' stories. They have names, personalities and real lives. The content for each personal narrative was selected based on reoccurring themes, what stood out in the interview and moments that meant something to the storytellers. Also, I presented demographic information including level of injury, education and employment history, marital status and family, age and gender, all pertinent to understanding the narratives. In the next chapter, I will present the narrative types utilized by each of the storytellers.

## CHAPTER FIVE

### Findings: Determining Narrative Types

*Narratives give rise to learning new lives - Engel & Munger (2007)*

#### Introducing Narratives

In this study, the findings could be categorized according to five narrative types. These are: (1) Second Chance Narratives (2) Familial Narratives (3) Rehabilitation Narratives (4) Change Narratives and (5) Reasoning Narratives. These narrative types emerged from the interviews with the six study participants, who spoke to me about who they were before injury, during rehabilitation and after the injury. The findings contained both personal narratives, the stories of the events and the participants' reflections of experiences. These narrative types crossed temporal lines, meaning each type contained stories of pre-injury, rehabilitation and post-injury. The narratives were not always told in a linear or sequential fashion. As such the identity narratives offered both stable and fluid, back and forth depictions of the participants' pre-and post-self.

In this chapter I will present the five narrative types as listed above. In doing so, I will describe the characteristics, roles and functions of each. I will begin with Second Chance Narratives, followed by Family Narratives in which self as family member, self as parent and self as child will be explored. Next, I will present the Rehabilitation Narrative focusing on individual transition and the role of the peer. Last, I will describe the remaining two types, Change and Reasoning Narratives. This chapter will end with a discussion regarding the thematic trends that were woven throughout these

narratives. The three themes were personal self, social self and autonomy and control discussed in relation to both the individual experience, independence and the role of others in identity creation.

## **Narrative Types**

### **The Second Chance Narrative**

Second Chance Narratives were distinctive in that they had a reflective and empirical dimension that provided permission for reinvention and re-authoring (i.e. meaning was ascribed to the injury as experienced and observed). Second Chance Narratives included stories about rebirth, balance and transition, where the SCI offered new appreciations and benefits, despite the challenges. The narrator spoke of an opportunity for change, with a chance to create and foster a new self. The narrator spoke of seeing the world, their lives and self differently. Also, these experiences were both life altering and stable, in that the injury was not the end of self before, but rather provided the catalyst for reinvention. The narration of these stories provided a platform for the revelation of aspects of a previous identity that were now considered displaced, instead of lost with the implied suggestion that the SCI provided the opportunity for these aspects of self to now be reclaimed.

These identity narratives, while describing the past, detailed experiences that for some individuals remained part of the present. For example, linkages were made between how life *was*, in anticipation for how life *could be*. These narratives spoke of a change in direction, while gaining a new perspective on life. The stories incorporated

an empirical component in that the narratives were not merely told but observed, lived and experienced as part of self. The experience of being injured helped the tellers appreciate what they had, the opportunity to go forward despite the new challenges, while transitioning to the next part of their lives. As a result, the creation of identity was present in narration of that second chance, where realizations of what was and the opportunity of what could be solidified self post injury.

Here is one example of a second chance narrative. Tailor told the story this way:

*And it was kind of like a rebirth and that's cause it was my second life. And so, it was this whole new thing and I just tried to enjoy it...I really did find that things looked better, experiences were more cherished. Ah, the landscape looked beautiful. Experiences were just better. It was like being born again I guess. It was kinda cool. I was lovin' that!*

We can see that for Tailor, the spinal cord injury was not a loss that resulted in a misplacement of self, but rather an opportunity for "rebirth." The injury was a chance for reinvention. There were times when the transition was difficult and Tailor said at one point, "I don't know how the stages of grief...what these stages of acceptance, recovery or whatever really are, but at some point it just wasn't all doom and gloom." In other instances, Tailor recognized glimpses of his "old self" (e.g. "positive" and "happy go lucky" personality). In the telling of the story, Tailor's new understandings of self, initiated by the SCI, began to solidify. The moment of transition became the moment of rebirth.

For Marcus, the injury was also considered a "second chance." He said:

*So I figure in part, someone upstairs, ah . My whole life was my work. My life was completely out of balance and I think this has put, placed Well, it's back in balance now. Now it's the other extreme where I'm looking after myself and now, hopefully I will be able to have a more balanced life, ah, with what's happened to me. So, it's a bit of a corrective action...So, ah, so it's a pretty interesting journey for me.*

This narrative presented a journey filled with new opportunity. Pre-injury, Marcus' life revolved around his work. He was consumed with his job and as he said, "life was completely out of balance." This "corrective action" was his second chance at a life. Marcus now had time to concentrate on himself, family, friends, interest and passions, things that were neglected pre-injury.

### **The Family Narrative**

Many of the narratives focused on the role of family in the midst of personal and social identity transition and construction. For example, all six participants told stories about their relationships with family, siblings and children pre, during and post injury. While these narratives were about the past, the identity that developed as a result of these experiences with family was very much part of the present.

These narratives spoke of the struggle to reinvent self separate from and in conjunction with others (e.g., being strong for your family when feeling vulnerable). Overall, the Family Narrative reflects three dimensions of the self: *self as family member*, *self as child* and *self as sibling*. These dimensions were evident in narratives that depicted the family as both a source of support and hindrance; affecting

independence and shaping dependency. The Family Narratives represents identity as socially bound, sometimes created *by* someone else, while at the same time providing consistency, a link between pre and post injury. By focusing on all three dimensions, family narratives represented the tensions between personal and social self following a forced identity transition. In some instances, one's ability to move on and create identity post injury was diverted or stifled by family expectation. In other narratives, family became an outlet to create new aspects of self (e.g., becoming a parent).

**Self as Family Member.** The first example is a narrative in which the personal identity was intertwined with family identity. The narrative illustrates the complexity of identity creation in the presence of familial relationships. Jeremiah began the interview with this statement, "*both my parents were teachers,*" which set the tone for the entire narrative. He rarely spoke of "I" separate from his family, except for one instance when describing his birth he said, "*Two years later, I think I was an oops, I came along.*" After each question, Jeremiah often responded with lengthy narratives about parents and siblings. In this particular narrative Jeremiah recalls himself in the context of his family:

*[My brother] was into sports and therefore I followed suit and throughout my life I played hockey. I was on the ice since I was two. Played hockey all around Canada. Same with baseball and badminton at the Canada Games and prior to going to the second one, I got injured in the summer and that winter was the second one and therefore I couldn't go. My parents travelled with me to all my hockey and baseball tournaments except for one, the Nationals... they travelled to every one except that one 'cause we went by just two vans... So they were good parents. I had a great childhood and you know, I couldn't have had a better childhood.*

Jeremiah told numerous narratives with a storyline that shifted back and forth between his siblings and parents, often ending with a statement that assured the listener that he had a good childhood. This reassurance served several purposes. First, the assurances almost acted as a coping mechanism in that despite all the challenges, setbacks and conflict, one part of his life was great. Secondly, the assurance may have indicated the end of the story, much like “and they lived happily ever after.” Thirdly, they appeared to serve as “the moral of the story” or the lesson to be learned (e.g. family was great; his childhood was great, etc.)

The Family Narrative also illustrates the strain an injury can have on family dynamics. Here is one example of a Family Narrative when life did not return to normal following the injury and the complexity of family relationships was revealed. Here are excerpts from that narrative:

*I guess afterwards, where my dad took it hard, I knew what was going on, so I took it well. And my sister eventually she got together with a guy [K.] in the States and him and my mom went to get something and they were at my Aunt's house and he said to my mom that I should go into a home. And I don't know what for, you know, because my sister knew... It didn't go over well, and that started a fight between my mom and her [daughter's] soon-to-be husband ... then K. said he didn't say that and my mom never lies so . So, you know, it put [my sister] in a hard spot. And what could you do?...my dad passed away in August and she never even came up to the funeral. So, which was another blow in my book... So other than that issue everything went along great after I got hurt but if it wouldn't have been for that issue I think life would have went along smoothly. But you know one comment can cause rifts and that sometimes happens in this sort of case. So, you know, when you get hurt the problems that arise from silly things and once they arise, there are things you can't take back and this thing that just happen two months ago, it something that can never be taken back.- Jeremiah*

This narrative describes the effect a spinal cord injury can have on family dynamics and both individual and family transition. It also speaks to the incongruity in that what once was a stable family dynamic became disconnected and disjointed; unfamiliar and unsettling. Dissonance occurred when all members were experiencing change. For Jeremiah, his identity was being re-authored in two ways: individually and socially. For example, Jeremiah's relationship with his father changed when he became more dependent on that relationship. His relationship with his sister changed when disagreements regarding his care placed the sister in a difficult position between her future husband and her mother. The family identity shifted as these relationships shifted and as a result, one of the few constants in Jeremiah's life was no longer predictable.

**Self as Parent.** In some instances, the narratives reflected self as parent. This Family Narrative was a sad reminder of how the SCI can prevent certain parts of the self from developing.

*I always wanted children but I didn't want children after I got hurt 'cause I wanted to be able to teach them how to play hockey, and to throw a ball and it would be harder not to, not to do that than to have children. I mean there was people that, you know, when we were going out that asked if I wanted to have kids and I said no. That it would be harder to have kids and not be able to throw a ball or play hockey or what have you, than to have kids. I thought about it a lot too. It was tough, but it was a decision I made long ago and ah, I don't know. I look at the fella I was talking about, had two kids beforehand and they were still young but not too young. But having a baby, which would be hard to look after at first, where his kids were past that phase, and that would have been hard on my partner or whether it would have been wife at that time, you know, to have it all on*

*her lap. So I didn't want that. So that's the way I decided to go. And I have no regrets. - Jeremiah*

How does an individual reconcile themselves to not being able to develop aspects of the self they had wanted to develop? Jeremiah justifies his decision to not have children by telling a story of personal agency. He had a choice and he chose not to, highlighting just one of the effects of SCI on identity narratives (e.g. parental narrative pre and post injury).

However, Destiny shares a different perspective on self as parent while also telling a story of personal agency. Her narrative focuses on becoming a mother post-injury:

*So, I had kids after I was injured and I liked it! It was the only time I ate right. It was probably the healthiest I've ever been...So, to me having kids was no different. I don't know what it's like for someone else. For me it was the only way I knew how to have kids. I looked after kids before, but you know, you just adapt. You adapt...For moms, you know, it's different. You just do it...[the kids] adapt, the same as I've done. Like it's all they've known. It's all I've known. So, it worked out fine.*

Destiny said at one point "I don't think I would have had kids otherwise." Destiny said that she would not have been "a good parent" pre-injury, but after injury she did it and "did it well." Destiny recalled carrying the children to term even though they were high risk pregnancies. This was a sense of accomplishment for Destiny in gaining a part of her self that was separate from the injury. The pregnancy, the birth and becoming a parent helped Destiny re-author her identity. Through the narration of these experiences Destiny illustrated how motherhood ended up defining her in a

tangible way. She realized that becoming a parent helped her develop aspects of her identity post-injury.

For both Jeremiah and Destiny, the SCI altered their pre-injury understandings of the self as parent. Jeremiah's pre-injury desire was to have children and the SCI altered that desire. Destiny's pre-injury understanding of self was that she would not have children and the SCI altered that understanding. Interestingly in explaining the impact of the SCI on their ability and desire to parent, both Jeremiah and Destiny tell stories of personal agency. Thus it was possible to see that the experience of agency was associated with making the decision to be a parent not with actually becoming a parent.

The following example of a Family Narrative was also related to self as parent. In this instance the children who were born pre-injury help to provide a continuous sense of self (as parent) despite the other identity ruptures associated with the SCI.

*Like I say, the hardest part was my kids were only young when I broke my neck. And knowing that I couldn't pick them up no more . But they got use to my chair. They would drive my chair and they're another thing that kept me going. Especially my middle guy, when I broke my neck, when he first came to see me and he made me cry 'cause he turned around and said "dad, will you promise me you won't dive no more." And I said, nope. I won't dive no more. And he said, "I come to look after ya." ...And you know, them saying "dad I still love you..." To this day, they still come down and there's not one thing they wouldn't do...You know, I've been injured 20 years and they still love me the same. - Hunter*

Hunter managed to incorporate aspects of self pre-injury (i.e., being a parent and being lovable) into his post-injury self understandings. Being a parent provided

continuity in times of forced transition. As such, the narration of that experience revealed the re-creation of a self where being a father was separate from injury.

**Self as Child.** The Family Narrative also represented self as child. Here, the identity narratives illustrated the parental role in identity creation. In one narrative, Nigel, as he was coming to terms with his injury, was met by an emotionally distant parent. Parental support during his transition and identity reformation was not available to him.

*Both of my parents are British, so you know, I inherited that British sense of carry on...But I think it paid a price because I remember it was two years after my injury and I was out in the backyard and dad was helping me do something and then I, I don't know what caused it, but I just broke down. Complete melt down. Complete melt down... I just completely had a meltdown and my poor dad, he didn't know what to do. Here was I bawling my eyes out and the last thing he wants is someone crying. The one thing he couldn't handle [laughs]. -*

This was a vulnerable and confusing time for Nigel. He was just adjusting to life with a spinal cord injury, only to be met with dissonance. The dissonance was between what he was feeling and how his dad was responding. This incompatibility was the result of discomfort experienced by Nigel's father, in the midst of immense change in Nigel's personal self. Nigel described his quest to redefine self after injury as tumultuous, being more of a personal journey that rarely involved his family. Nigel told this story of identity reformation within the context of parental absence.

In sharp contrast, the next example of a self as child narrative focused on the presence versus absence of family during recovery. This narrative represented the

point when Tailor also experienced dissonance, caught between giving and receiving support, being brave and being vulnerable. Here he talked about the time when everyone wanted him to be strong, a time when he felt anything but. Aspects of Tailor's identity changed following the injury, but he was surrounded by people who wanted him to be the same. In this narrative, Tailor reframed "being strong" to mean "independence," which occurred when he took back control and decided who he would become.

*And they all wanted me to do better [mocking voice] and I wanted to make people feel good when they came down, so I would like, you know, tell them I'll be alright and everything...everyone comes and it's just a shitty time. ...And then, so, the friends and family, everyone is there to support you and you just kinda fell a little but responsible for that, kinda put on that brave face that people would like to see. And you know, you wanna be strong. My brothers and everything just kept saying to be strong and being strong was actually independence. - Tailor*

Tailor also shared a narrative about returning home after rehab, which spoke of the complex balance of family, self, necessity and remaining independent. This relates to Bamberg's (2004, 2010) and Yoshida's (1993) thoughts on transformation and identity creation, suggesting that when traumatic or unpredictable change events occur, one begins to search for, construct and maintain meaning (Bamberg, 2004; Yoshida, 1993).

*Well, I had moved out right before my accident. I was done with living at home and I had lived at home for a long time and moving home meant moving back with my parents and it was like, oh my God, I don't want to do that either. And plus there's stairs and everything. So we had to get it accessible. So [my parents] brought in some carpenters and they put this wrap around ramp. It went from the bottom floor to the top floor. So I was able to move into the bottom floor and then go up around the ramp to the*

*kitchen to join everyone for supper...It wasn't so bad. [My parents] gave me a lot of breathing room. - Taylor*

The last example of a Family Narrative belongs to Marcus and it outlines the difficulty of accepting support for fear of relinquishing independence. In this instance, control became a way to regain autonomy, through the linking of pre-self with post-self.

*Well of course my family ...I'm divorced but I'm still very close to my ex. So she's been helping out and I have two children. Two girls....So when I first ended up in hospital they wanted to come here immediately and I said no, please don't. Cause you know, you come here, and I'm in bed, and what are you gonna do? Sit here and hold my hand for like two or three weeks? Come when I need you. When I'm out of hospital. Which they did...there's this thing that I don't want to be a burden on them either because I was always very, very independent. So I'm quite cautious of what I ask them for. - Marcus*

We can see that participants' Family Narratives depicted the effects a spinal cord injury can have on social relationships, specifically relationships with parents, siblings and children. McAdams (2011) proposes identity narratives are "life as reflected instead of life as lived" (p. 12). He goes on to say, identity narratives are the internalized and evolving story of the self that a person constructs (McAdams, 2011), as was the case with Family Narratives. Even though identity narratives are understood to be a subjective and historical account of life, they allow the individual to elicit experiences that have meaning, thus contributing to identity formation (McAdams, 2011, p. 100).

These Family Narratives melded the unfamiliar with the familiar. They wove together tedious threads of recovery and displacement with former self, balancing independence with support and the presence of family with the struggle to find new self. In some instances, the self depended on someone else's version of who they were supposed to be. In others, the narration of those experiences helped solidify self and create meaning. This reflects Vignoles, Schwartz and Luyckx's (2011) depiction of identity as both individually and socially constructed as outlined in Chapter Two. Identity often encompasses understanding oneself in conjunction with others, while remaining unique and establishing individual agency.

### **The Rehabilitation Narrative**

Many narratives surfaced with regard to rehabilitation, drawing on that particular experience during injury. This type of narrative was also present in each interview and was based primarily in the past. For some, the focus was on the rehabilitation centre experience. For others it was the peer relationships made at rehab that infiltrated their stories.

*But you know, rehab was... I got to know L.M. and I think it was him that helped me along in there. He turned around, and when he came in, I was lying flat and he turned around and said my name is L. and he asked me what happened to me, and I told him. I asked what happened to him and it was the same thing. He broke his neck diving and we got along. We went yard salin' and the things he was doing to me was ...He'd make me laugh...He made a smile on your face. That helped me big time, right there...And DM would take us out to a bar, to show us that life ain't over. That you could still do, if you put your mind to it, you could still do things. I was 30. 20 years this July. And there were times when that was hard. - Hunter*

*Oh! I got hurt two months after a great friend of mine. And that was a Godsend, tell you the truth. For each of us I think. I knew what was going on and what happened. I, he learned stuff from me, I learned stuff from him. What else can I put, can I say? We're two peas in a pod. For the longest time, we still go around a lot and when I was doing my accounting and had the sore we stopped seeing each other near as much because I'd be so busy. But now we're active going around a lot together and talking to each other a lot. - Jeremiah*

The Rehabilitation Narrative also represents success and failure, highs and lows, agency and lack of control. As Pals (2006), Lohne (2007), and Dunn and Burcaw (2013) suggest, difficult life experiences challenge the narrative construction of identity. In some instances it produces a narrative that incorporates both interpretations of pre disability self with post disability self, allowing for a duality of sorts. This occurs in the Rehabilitation Narrative where the actual construction of these narratives provides the opportunity to revisit experiences while living in the present, both becoming central to individual functioning (Pals, 2006) and reconciling all aspects of self while providing meaning and purpose. Rehabilitation was a time during which the realization of forced identity transition began to sink in. For example, there were moments of improvement in functional ability, tainted with harsh realization that function would not return.

*When I got to the rehab, knowing I was never going to move again and... When I was in the rehab I kept myself happy with hanging around with a bunch of people that were in there and then when I left the rehab I got real depressed... 'Cause going from having a lot of friends to just going to my apartment with nobody. Yeah, I got real depressed. I ended up back... - Hunter*

For many, rehab was the moment where they became aware that their bodies were different and they had to learn to manage this altered body. It was the forced transition of physical self. When referring to this experience, Taylor said, *"my environment was a lot more restricting and of course the physical challenge was a little bit tough and I had to learn a lot of patience you know, causing dressing yourself takes minutes compared to seconds and stuff like that."*

The Rehabilitation Narrative was rife with turning points from friendship to physical and emotional adjustments and identity shifts that were painful and difficult to fathom. These narratives represent a time that was fluid and dynamic, moving from despair to hope to acceptance, and sometimes back to despair. The metaphor used to describe this experience was *"crests and waves."* This was the moment when new identities were starting to be authored and take shape, in the midst of highs and lows. This narrative type compliments Yoshida's (1993) notion of an identity pendulum, where she posits that the reconstruction of self is like a pendulum, one that is dynamic, negotiating between disabled and non-disabled self. This idea acknowledges the aspects of former and current self in identity formation post SCI, which is illustrated by a dual directional process.

The Rehabilitation Narrative usually focused on *"the bubble"* - the safety net that was rehab.

*So then I got to go to rehab, which was like the Promise Land! When they tell you, you get to go to rehab [mocking voice]... and finally you get there...You're like okay, it is better but you know, it's still a hospital. So*

*you're sharing a room with four, or three other people. And, ah, one of the roommates was a, we became good friends...Me and the other guy, so we had a good time! Actually, it wasn't so bad. But they say that your bubble will burst when you leave rehab 'cause it's the real world. And then you hit the real world and that's when it hits you really bad. But I didn't see it like that. I just kinda, it was better to be out of the rehab and out again. Free. - Tailor*

*I remember being home sick...And then at the rehab it was physio and getting back into the groove of things. I loved rehab. Loved it! Well, I didn't like it, but the people there was great. But being at rehab for four months was... When I started getting home on the weekends it was almost like a relief getting back to the rehab because everything there was set up for me cause when I was first coming home weekends and stuff I couldn't go back to the trailer cause it wasn't equipped sorta thing... So when I went back it was sorta like a relief. It's bitter sweet like. Like it's hard to explain. Like, it was comfortable at the rehab. I wouldn't wanna go back now but it was like a bubble. Like the dome. It's your own little world. It's a safety net. That's probably why I liked, well I didn't like going back but like I said, it was bitter sweet. - Destiny*

For some, rehab became a place to safely navigate and negotiate identity experiences without fear of moving too quickly away from or towards former self and new self. They were surrounded by peer narratives that spoke of similar circumstance and experience, supported by people who knew what it was like and who had been there. Emphasizing the key role peers played in identity transition is a defining characteristic of the Rehabilitation Narrative.

For others, the rehabilitation experience was “depressing,” where they gave their experience meaning through comparison with others.

*When I was in the hospital, rehab especially, man, it's a depressing place. All these young kids, you know, injured teenagers, 17 and 18 years old injured in an accident. BANG! [emphasis] Right? Then this older man that I*

*met and others, right, and there's a lot of depressed. It's a depressing place. I think it was different for me because I got to live a life. I've thought about that a lot actually because there was one young kid in there and I sort of, tried to mentor him the best I could and he was having a lot of difficulty dealing with it. Right?...He was depressed, right. Yeah, so you can only do so much right. You know, I felt for the guy. He's got his whole life ahead of him. I've had a wonderful life behind me . - Marcus*

The realization that “it wasn’t as bad as it could be,” was a sentiment meant to bolster hope in individual circumstance. For Marcus, helping and assisting others was a way to foster independence and maintain aspects of his previous self. He once again wanted to feel as if he was needed, that he had something to contribute. It reignited a sense of purpose that has been momentarily displaced. As Valvano (2012) proposes, this sub-narrative concerned with *helping* and *purpose* became a fundamental way of expressing oneself after the SCI, by providing continuity and stability between the aspects of pre and post self (Vignoles, Schwartz & Luyckx, 2011).

For Nigel, the Rehabilitation Narrative reflected a time he would rather not recall. While rehab may have represented “safety” for some, it represented dependency and frustration for Nigel.

*I was in the rehab centre; I was in the hospital for four months...It was just awful! It was just awful...All I wanted to do was get out of the hospital. So I had the fastest rehab at the time, I mean I was, to be, I was home four months after my accident. That was pretty much a record and I mean I still had to do a lot of out-patient physio and I was driving down to physio for, but I just wanted to get outta that place so badly. I hated it. I just hated it!*

In this example, identity was connected to separating oneself from the rehabilitation environment. It was returning to normalcy that was of benefit to Nigel. It was the

connection with the context of his past self that would foster the creation of post-injury self. These two examples illustrated the difficulty and discomfort with transition, even in a “safe” and “supported” rehabilitation setting. In the end, each of the participants wanted the opportunity to develop their identity on their own terms and in their own way.

Being admitted to a rehabilitation centre was something all six participants had in common. However, their experiences appear to be very different. Some found solace in the peer experience while others found it to be depressing. Some used it as the first point of transition while others wanted to escape and return to the safety of home. Some found lifelong friends at rehab while for others it was a reminder of what they lost. Whatever the narrative, these experiences helped participants shape who they became post-injury.

### **The Change Narrative**

The Change Narratives were used to express experiences of change, negotiation, acceptance, adjustment and identity transformation. They were generally told as a way of explaining the acceptance phase after injury. Dunn and Burcaw (2013) may see it as coping, that is “emphasizes existing or potential assets while broadening scope of values beyond those compromised or never realized precluded by disability” (p. 151). Coping is evident in the “beliefs storytellers develop and rely on to understand, navigate and share their life experiences with others” (p. 151) and become vital in the creation of identity narratives.

*You just have to deal with it. You can either choose to accept it and move on, or you can become bitter, angry and isolated. - Jeremiah*

Participants mentioned coping along with images of a past self that no longer represented the current self.

*I'm just me, right, and that's the way I dealt with it. So, those people have asked, Marcus, you should be talking to people who are having trouble, with this sort of stuff, with the transition, but I don't know whether I can help cause it's just me, right. Not them. So you got to deal with it in your own way. You know, it's easy to say be positive but if you don't have it inside of you, you know. Where do you find it? - Marcus*

This type of narrative acted as a bridge between who participants were pre-injury and who they were post-injury. These narratives were based in past, present, and future, creating continuity of self in response to shifting circumstances. Change Narratives represented the point where post-SCI identities were crafted and bound to new truths.

*I'd like to say that I've helped quite a few people. It has helped me a lot to deal with my injury. By showing them what I went through... I bring them down to my place. I'll show them where I can't use my hands or anything, how I can pick up things, how I get around in my apartment. I don't need no one there all day, 'cause I show them how they put water out for me, my pills, how I pick my pills up, put them in my mouth. You know, you see their smile on their face saying, well okay. If he can do it, then I can do it. - Hunter*

These narratives represent a process of constant change and adjustment, highlighting the difficulty of finding self when you do not really know what it is you are looking for.

*I lived it the best I knew how...Being injured was devastating at first but I don't, I really don't remember going through any sort of depression at first. - Destiny*

Change Narratives also represented moments when “*dealing with it*” was the only option for moving on.

*I just had to make things almost the same but just using my imagination to make myself happy, I'm happy. I'm content now. Twenty years is a long time. You can either sit there and mope and mope and mope, and when you're moping no one is going to wanna come visit ya. - Hunter*

Participants spoke of regaining their independence, as defined by them, despite losing physical ability. The participants spoke of self in the present and new self, not looking back at what was but looking ahead to what could be. For some the change was devastating but they lived through it and their new self was wiser, stronger and ultimately changed. They also described the contradictions and commonalities that existed, where the metaphor “*same but different*” (Destiny) was used to describe self as both continuous and discontinuous. As such, these narratives portrayed the meaning of independence and self-sufficiency in the midst of uncertainty and change. Participants used Change Narratives to express a sense of agency and control over one's circumstance while understanding perceived and defined limitations.

*I mean my environment was a lot more restricting and, of course, the physical challenge was a little bit tough and I had to learn a lot about patience, you know, 'cause dressing yourself takes minutes compared to seconds and stuff like that. So, then I thought I grew as a person. I thought it made me a bit more spiritual. A little more understanding and it's just kind of a different perspective. I just tried to take all the positives of this new life that I had and life is about experiences, and here's another experience, so I kinda accepted it early on I'd say and I don't even know what that means. Accept it but I wasn't in denial. I mean it happened. There's nothing I could do about it and I might as well keep living. - Taylor*

Lastly, these narratives were always being (re)negotiated and (re)constructed as new experiences arose. Sparkes and Smith (2005) state that “a self in time can only exist as a narrative construction” (p. 82). This construction encompasses many facets of self and numerous identities, often worked and reworked, revised and created. These identity narrative constructs guide the actions of the individual, fostering an understanding of oneself as “embodied” (p. 82). The Change Narrative helped the individual discover new truths about perseverance, strength and the human capacity to recreate identity.

*At some point, I just wasn't all doom and gloom... And so things got better...I was only going to be 24 years old once in this life and I was going to make that the best I could...I just kinda said, "OK Tailor. This is totally different," you know. "You're not going to be able to do this."...So, like, you could do 10,000 things in your life, well you're only going to do a handful of them anyway. Now I could only do 9,000 and still only do about a handful of them... - Tailor*

Through Change Narratives, participants highlighted the process of emotional, mental and physical transformation after injury. They also spoke to the real, everyday experiences of living with a spinal cord injury.

*And they came in and completely did my kitchen and gave me the cupboards that go up and down and all that stuff. And I said that it was the first time, okay was three years ago, in 27 years that I didn't have to put my dishes in the drawers cause I had all my dishes in the drawers right and now I can put them in the cupboard. I thought it was amazing. To someone else, they won't really think about that. But someone in a chair. It was a big deal. It was a BIG deal. - Destiny*

These narratives also told of the repercussions of sudden transition:

*I don't recall throwing things or that type of thing, but I'm sure I was angry at some point. Like high school. It was hard enough as it was. And like I said I was a great dancer and to go back to the prom was very tough. I, but I wanted to do it and there is that sense of community. That's what it is! Community. If you have a sense of community, whatever that community is, I think your transition is so much better. And the rest of your life is shaped by it - the spinal cord injury. It had to. Things would have never went the way it did. I would have never gone to university. You know, I think about this, not infrequently, especially the last little while, I don't know why. You know, one could argue that it was the best thing that ever happened to me. - Nigel*

*Like I say, I think you learn a lot about yourself. About dealing with this thing. It's a major event in your life. BANG! [emphasis] So, , Self? That's a tough question! I, I haven't really thought about that 'cause I'm just sort of dealing with it. Going with the flow and then finding different strengths that I have. And challenging, ...It happens naturally, like doing all the research keeping me active intellectually and keeping me challenged. - Marcus*

These narratives represent the realization that sometimes “*you just have to deal with it,*” which is reflective of a forced identity transition as opposed to chosen identity transition. While the Change Narratives were being (re)negotiated, they were also being transformed by way of action and lived experience. Furthermore, transformation required a constant process of unpacking, (co)narrating, (re) (co)constructing and (re)structuring, creating rich identity narratives of self at that moment.

### **The Reasoning Narrative**

The Reasoning Narrative fluctuated between fate, self blame, and confusion. This narrative type was sometimes grounded in logical reasoning when individuals

tried to come up with a deductive explanation as to what happened, to diminish any sense of blame.

*Ah, it was at the beach. I wanted to go back into the water one more time...Just one more time and no one else would go. You know how you run in and dive in and when I dove in, I didn't put a mark on me, beside a red mark on my nose. I was wide awake. All of a sudden I couldn't move and I knew what happened and I couldn't believe it happened...Earlier that year I had a close call and that is a possible reason for the injury...The Doctors could not find a cause for the injury. There were no obvious physical injuries to face or body. No rocks. No diving... - Jeremiah*

That there was no medical explanation became a narrative that got told over and over while searching endlessly for a reason - the "Why". Without that closure, it became difficult to move on. It is the actual construction of this type of narrative that provides the opportunity to revisit experiences while living in the present, both becoming central to individual functioning (Pals, 2006) and reconciling self with experiences while providing meaning and purpose.

The Reasoning Narrative represented the relationship between knowledge and anticipation, knowing what's happening and preparing oneself for the fallout. For example, in this narrative we see someone who used First Aid knowledge to comprehend what happened, without fully grasping the effects of the injury and what that meant for the rest of his life.

*So, we go sailing down the hill, she fell off half way through and me being the macho guy, I carry on and sort of go sailing over the cliff and I land. I am sitting on the toboggan. So I have a complete compression. I just literally went in two and broke my back. I knew exactly what had happened 'cause I had taken - I was a boy scout amongst other things so I had some fairly good first aid training. And I knew that when (pause)... - Nigel*

Other Reasoning Narratives explored the presence of divine intervention, where fate had a hand in the events around the injury. For example, Destiny believes that *"life is predetermined from birth."*

*Things happen for a reason. I sorta take something and turn it around so that there's a reason behind everything or something, 'cause you'd... I'm sorta justifying it or something. My coping skill. That. And I just did it I guess. - Destiny*

This type of narrative can be understood as relinquishing any sense of responsibility or maybe it is an example of taking control by accepting it. By saying it was up to someone else, implied a lack of agency and control over the situation. It became easier to accept the forced transition and the impending results when the events were pre-determined. On the other hand, accepting it meant that they had control over what happened next and were able to own their experience.

The Reasoning Narratives also inspired comfort after periods of reflection, when the individuals sought to understand why.

*Things happen for a reason. There was a reason for it. So, would things have been different if I was injured? Who's to say? I don't know if I'd have these two kids or not. I don't know. Who's to say? I don't know if I'd be with that same guy or I don't know. I know I'm a different person to some extent... But, you know, I consider myself the same person. Everybody says I'm the same person except I'm sitting down. And that makes me feel good. 'Cause I didn't want to change into a hateful bitch, you know. Or feel sorry for myself, which I DON'T. I don't. - Destiny*

However, the comfort was not in the answer itself. Rather the comfort was in the seeking, processing and unpacking of the answer, which became crucial in identity construction. These narratives were subject to constant reflection post injury, as

discerning the why became a narrative in itself that was frequently re-authored as individuals longed to understand their experiences. In the same way, the narration of those experiences also confirmed and validated what happened, providing solace or at the very least comfort.

Furthermore, the Reasoning Narratives were crucial to transition and transformation. Individuals sought comfort in the knowing, whether real or perceived. Even though the outcome was somewhat prompted by their participation in the study, it was evident that the narration became an outlet, processing confusion, sadness, and loss in the middle of unexplainable circumstances, helping situate self while giving rise to new learning (Riessman, 2002; Bamberg, 2010; Lohne, 2007). In turn, the narration of these experiences helped make sense out of a difficult situation that served to make amends with past selves, as discussed by Goffman (1963) and Riessman (2002). Perhaps, it was matter of getting the storytellers to think about their experiences differently, from a place of meaning and purpose. In the end, it was a circular process where one informed the other.

### **Unpacking Narrative Meaning**

While the narrative types represent experiences of each participant, what do they reveal about identity transition? Is identity reflected in narrative? What can we learn about identity? In the next stage of analysis these five narrative types are interpreted with respect to three main themes: (1) personal self, (2) autonomy/control and (3) social self. I discovered that all three of these aspects of self were evident

within the five narrative types, albeit in different ways. Each theme will now be discussed in turn.

### **Personal Self**

Every participant experienced a shift in personal self as a result of the spinal cord injury. The struggle involved in reconciling aspects of past and present self were evident in each narrative (e.g., physical, emotional, etc.). The narratives reflected the uncertainty and dynamism of identity. Who would they become? How would the injury affect who they are and who they know themselves to be? The experiences were often dichotomous at the beginning. Participants understood themselves as either able bodied or "disabled". Later as self developed, experiences of self were richer and more fluid. The experiences associated with the reinvention of self became more important, instead of remaining fastened to narratives that only portrayed and illustrated self without an injury. The emphasis was on reconstructing self, exploring new identities and experiences.

These narratives illustrated the transformative process of identity creation in a fundamental way and, consequently, highlighted the role of narration in identity transition. The effect of SCI on identity narratives was a simultaneous experience that included both the disassociation with self and the invention of self in hopes of constructing a transformed personal identity. This was illustrated through Destiny's notion of "*same but different*," a delicate dance between past and present aspects of personal identity. For Taylor, transformed personal identity was captured by way of the

*"stages of acceptance, recovery and whatever they are,"* where at *"some point it wasn't all doom and gloom."* He goes on to say that every time he could see glimpses of his old self he was happy, yet he knew things *"were totally different."* The narratives illustrated the difficult process of creating oneself in both the past and present, negotiating aspects of non-disabled self and disabled self into current understandings.

The narratives also reflected personal self as it alternated between emotional dichotomies and uncertainty, as was shared in several rehabilitation stories. For example, many of the participants were happy knowing they were going from the hospital to the rehabilitation centre, yet it was there that they learned of the severity and consequences of such an injury. For example, Taylor called it the *"Promised Land"* despite being presented with all the things he *"couldn't do."* Then there was Hunter, who was told the extent of the injury at rehab, told that he would only be able to *"shake his shoulders."* When asked what life was like now compared to before, he said, *"it's almost the same."* Each person was passing through turning points of realization and insight that, when combined, represented the complexity of identity creation.

As such, the lived experience during injury and post-injury involved the reorganization of identity based in continuity as well as discontinuity. The disruption of self combined with the familiarization of new realities resulted in narratives that highlighted aspects of self embedded in (1) cause and consequence, (2) hope and despair, (3) new beginnings and rebirth, and (4) sameness and difference. For

example, Marcus shared narratives of cause and consequence when he spoke of the surgery, which saved his life but left him with paraplegia. Marcus also spoke of his life being “*out of balance*” pre-injury but “*back in balance*” post injury. For him, the injury was “*a corrective action.*”

Jeremiah shared stories of hope and despair, especially when recounting his experiences with education post injury. He said, “*[the professors] said I wouldn’t be able to do it and I said I’ll do half a year and if my grades aren’t good then I’ll do it in two. I did it in one [smirks].*” Jeremiah shared how he hoped to go to medical school but knew that would not be a possibility as a result of the injury, and compromised, opting for something that required less physical ability. While Jeremiah finished his first degree, health issues prevented him from completing his second degree and furthering his education, which was disappointing. Despite all his attempts, he often struggled to find balance between disability related health issues, ambition and education.

Taylor told of new beginnings and rebirth. He said at one point:

*They say that your bubble will burst when you leave the rehab cause it’s the real world... but I didn’t see it like that. [I was] free and it was kind of like a rebirth and that’s cause it was my second life. It was kind of like this whole new thing and I just tried to enjoy it. Things looked better...The landscape looked beautiful. Experiences were just better. It was like being born again. I was loving that.*

Taylor was quite aware of his new reality and embraced it.

Last, Destiny illustrated continuity and discontinuity of self when she spoke of sameness and difference. She said at one point, *"you know, I consider myself the same person. Everybody says I'm the same person except I'm sitting down. And that makes me feel good."* Yet, in another part of the narrative she said, *"I know I'm a different person to some extent. I am more patient, well sort of (laughs)."* This delicate relationship between pre and post self was present for several participants.

### **Social Self in Relation to Peer and Family**

The narrators also spoke of self in relational terms, the social self. In some instances, these social experiences influenced the construction of identity. Some narrators spoke of responsibility to the other, the presence of self in other and the construction of self in relationship/community. Narratives reflected the understandings of self derived from membership in social groups, such as one's family, friends and peer groups. Hunter and Jeremiah found purpose in peer support groups as both volunteers and mentors. For Destiny, identity was linked to becoming a mother. For Taylor, revisiting his interests in sports was the key. These social relationships contributed to the (re)authoring of self through a recursive process of transformation where aspects of past social self (e.g. athlete) recurs in the present, social self, post injury.

In some instances, these relationships played an integral role in who they became after injury. Parts of identity were defined in accordance to role (e.g., parent). Others were influenced by physical or circumstantial affiliation (e.g., injury, rehab). In

many instances, multiple social identities were at play, complicating transition, yet providing a framework for social self development. For example, Jeremiah grounded self post injury in family relationships and relied on his role as family member, child and sibling to recreate self. In essence, these social relationships provided meaning and context to his post injury narrative.

The development of the social aspects of self were important to overall identity development. The ability to separate self from injury, a crucial aspect of the post-injury identity transformation, was depicted in many of the narratives. Some participants spoke about an aspect of their pre-injury self (e.g., independence from parental influence), that remained despite the injury, and as such provided some identity continuity post injury. For others, social identity, specifically family identity, became the foundation of self.

While each narrative included themes of personal self, autonomy/control, and social self, how these themes were articulated varied. For some participants, meaning was found in the re-birth narrative. For others, meaning was represented in family role and support. In each instance, meaning construction through narration coexisted with identity reconstruction. The significance attached to events and experiences was evident in the identity narratives shared by all six participants. Critical turning points were found in those very narratives, teaching us about the creation of self post-SCI. Despite the forced identity transition, core aspects of self remained as they worked their way through new experiences, new narratives and new identities.

## Autonomy and Control

Postmodernist notions of identity allows us to understand the ability to change and reinvent the self in relation to changing context (Fook, 2002). In these stories we see identity as changing with the ability to empower oneself through independence. Independence was a word used by many of the participants and for them, it meant freedom, choice and self-determination. For example, Marcus said:

*the big thing...is this not being a burden on [friends and family], so that's weighing heavily on me...The lack of independence is difficult to [accept], you know. At times, I'll [hire] someone. I'd rather pay someone than ask for help from family.*

Nigel said he had "a certain level of independence" because of where he lived. He was free to come and go as he pleased and did not have to rely on accessible transportation. He was able to wheel given the landscape of his neighbourhood or drive himself if needed. For Destiny, independence was very important. She told a story about the purchase of a power wheelchair so she could "walk on the beach" with her daughter.

*If I wasn't for [funder], I would never have got it, cause they paid for it. It was over \$20,000. That is sad... What I've been able to do! It's filled a part of my life that was missing. I said, 'where have you been all my life.' 29 years without something like that, cause my other scooter would never go the places where this other one goes... The independence! You can't put a price tag on that! [The funder] gave me a hard time at first, they weren't going to approve it. They didn't want to...[The funder] said what would that mean for you? And I said, my independence. That's what I said to them. What would it mean to me?...All I could say was independence, cause that's what it was. How else can you define it? - Destiny*

For Taylor, his independence was threatened when he had to move back in with his parents post injury. He said, *"I had moved out right before my accident. I was done living at home...moving home meant moving back in with my parents and I was like, 'oh my God, I don't want to do that'."* Moving back home meant relinquishing some of that independence he had gained pre injury. He ends that story by saying, *"It wasn't so bad. They gave me a lot of breathing room."* Ultimately, Taylor was given the freedom to make his own choices.

One of the effects of the SCI was that one's self-understanding as "independent" changed because the participant started to understand "independence" in a different way. Independence was not necessarily defined by the freedom to *move* one's body but by the freedom to *think* for oneself. For example, choosing where they lived, the ability to come and go as they wanted, the ability to decide what type of attendant care they received and whether or not they even required support were all examples of redefining independence. The ability to think for oneself was vital to the process of establishing self post injury. While physical self may have been compromised, one's ability to think independently was very important.

When someone sustains a spinal cord injury, the individual's identity becomes challenged in an instant. The forced transition causes changes in all aspects of self, including one's ability to exert control. In the case of rehab, there were times when the individuals struggled to regain independence and felt as if they had no control over their lives. For example, following a spinal cord injury, people are admitted to

hospitals and rehabilitation centres where control is often diminished in favour of medical mandates. During this time of physical transformation, other aspects of self were also transforming. As illustrated above, the injury caused significant disruption to all aspects of identity from loss of physical function to loss of agency. Suddenly, participants were thrust into the realm of absolute vulnerability as they began piecing together the parts of self that had been displaced.

However, at times autonomy and control were exercised in the rehabilitation environment through the breaking and bending of rules (e.g., drinking, ignoring visitor limits, early discharge). The participants sought control in any way possible, which sometimes meant not conforming to expectations. In other instances, some said they exerted control by achieving academic accomplishments, maintaining demanding careers post-SCI, and excelling in athletics. While this construction of empowerment as independence has ableist undertones, this was their understanding and interpretation of those experiences.

For Jeremiah, he expresses that he exerted control over his situation by choosing not to have children post injury. This was his decision and while it was difficult, he knew what he wanted and remained in control. For Destiny it was choosing to have children post-SCI, even though many told her not to primarily based on medical discourses that cautioned against it. After everything changed and regaining control seemed impossible, these participants found ways to do just that. For Jeremiah and Destiny, they did not conform to social pressures or the skeptics that

tried to dictate what they could and could not do. On the other hand, this could be mistaken for binaries of dependence (as bad) and independence (as good), where dominant social, ableist discourses dictate the measure of ability. Either way, their experiences were their own and if self defined control could be misconstrued as disempowerment, we should err on the side of the storyteller. It does not mean that we cannot question, but we must also respect what is being shared.

In other instances, autonomy was sidelined as opportunities ended in disappointment due to disability related health complications, as was shared by Jeremiah and Hunter. Jeremiah had to withdraw from university due to persistent skin issues, which kept him in bed for months on end. For Hunter, it was depression following the injury that threatened his autonomy. All of the narratives shared above reflect the struggle of finding and regaining independence, control and autonomy following a spinal cord injury. The disruption was often met with the determination to succeed, regardless of circumstance. Independence was not defined by society, but individually by each and every one of them. Much like control, independence was shaped in individual circumstance, from living alone to being able to feed oneself. It varied for each participant and was tied to level of injury, relationships and expectations. Ultimately, the notion of "*carrying on*" ignited a desire to regain control over one's life and identity.

## **Summary**

In this chapter, I presented the findings using five narrative types that emerged from the findings. Each narrative type referenced self, meaning and relationships.

Narrative excerpts, taken from the interviews, were used to illustrate how participants understood themselves before injury, during rehabilitation and after the injury. In turn, the findings presented a layered, critical conception of self during all three stages of transition. Lastly, the findings showed the complexity of identity narratives in the aspects of personal self, social self and autonomy and control.

## CHAPTER SIX

### Discussion: The Role of Narration

*Narratives help fill the space between what happened and what it means. - Kramp (2004)*

#### Reestablishing Context and Reiterating the Importance of Stories

In this study I wanted to find out how the telling of stories creates identity and what stories tell us about the transition of self post injury. Narration is the act of telling, whereas the narratives are the stories told. The findings of this study suggest that people narrate in an effort to solidify, make sense of, (re) create, (re) structure and define self following forced identity transition. This narration reflected self in a particular moment where the telling was grounded in and based on contextual factors such as present circumstance, reflection, and time past. The narratives contained within this study highlighted important relationships, roles, transitions, challenges, as well as personal self, agency and social self. Both the narration and the narratives provided insight into the role of telling stories about self and the transition that occurs following a spinal cord injury.

In this study, I identified five narrative types. The narratives were: (1) Second Chance (2) Familial (3) Rehabilitation (4) Change and (5) Reasoning. When the narratives were told this way, the participants conveyed moments of rebirth and a second chance to do something different with their lives following the SCI. They spoke of family, siblings and relationships that sustained, provoked and shaped them

following the injury. They told stories of difficult transitions and the challenge of finding self in the midst of the most trying of circumstances. They described moments of unwavering support, connecting with those who had been there while they dealt with the realization that things would never be the same. At the same time they spoke of the moment - the moment of forced identity transition. They described how they were injured and the second they knew. Hence, we can see that each of the narrative types provided a container for complex self, drawing on aspects of personal and social self, while giving these experiences meaning.

This study is important in that it illustrates the linkages between narration, stories, change and identity. These linkages have a universal appeal in that everyone has a story, along with the ability to author who they are and who they become. This study contributes to the understanding of the effects of SCI on one's self-understanding from the perspective of the storyteller. The study offered first person accounts of self in the midst of transition after a spinal cord injury. Unlike other studies on SCI (Yoshida, 1993; Sparkes & Smith, 2005; Valvano, 2012) where the goals were to understand quality of life, adjustment and living with a spinal cord injury, this study offered a perspective of SCI focused on narration, narratives and the meaning attached to each experience. This study did not collect stories to merely fulfil qualitative interview requirements. Rather, narration occurred and stories were collected to unpack the messiness, vulnerabilities and discomfort typical of identity transition.

### **Purposeful Storytelling**

Like McAdams et al. (2006), I have concluded that “we are all storytellers, and we are the stories we tell” (p. 3). There was the “self-as-teller” through the process of narration and “self-as-the-tale told” in the form of identity narratives (McAdams et al., 2006, p. 3). In this study, narration was not simply used as a way to rehash past events, in hopes of comparing one forced identity transition to another. Rather, the narratives presented were grounded in a common experience (e.g., SCI) that instantly changed aspects of self. While the resulting narratives were not all encompassing, they spoke to the ebb and flow of identity construction, taking into account a disjointed self as well as the process to reclaim self after a spinal cord injury. Now that I am nearing the end, I wonder, what exactly was the purpose of storytelling? This study confirmed that narration: (1) links pre-self with post-self, (2) gives experiences meaning, and (3) provides an outlet for self expression grounded in ‘reality.’

### **Linking Identity Pre and Post-SCI**

Narration following a forced identity transition helped link pre-self with post-self, providing stability and continuity in the midst of change. Narration post injury allowed participants to express various aspects of self, both pre and post injury, tapping into who they were and who they are. For example, participants’ narratives incorporated parts of self that still existed despite injury (e.g., physical self as athlete) and parts of self that had changed (e.g., physical self and level of independence).

Furthermore, it was evident from the data that aspects of self pre and post injury did not exist separately in time and space. Rather, they existed in relationship with each other through the process of narration. Identities were negotiated as the individual described the contradictory nature of living with a spinal cord injury. For example, the self can be both freed (rebirth) and limited (loss of bladder function) by injury. Yet, ironically, narration also provided consistency, a fluid identity during the transition and adjustment phases where the phrase "same but different" often surfaced. For example, Taylor spoke of his interest in sports pre and post injury, yet realizing that what he participated in post injury would be very different. Identity narratives helped reveal how being a brother, son, daughter, mother, and father were maintained despite the injury. In some instances, participants were still driven, educated, and daring despite physical limitation. Ultimately, these narratives demonstrated linkages between the past and present self.

### **Giving Rise to New Meaning**

It is my interpretation and understanding that narration gave experiences meaning. Like Bamberg (2010), I discovered that narration became a tool for identity construction and meaning making. For example, the Second Chance Narrative became a way to assign roles, articulate identity transformation, and unpack the meaning of what participants experienced. Narration was not simply a process to simply find out who they were and what they experienced. Rather, the resulting

narratives revealed how identity was constructed, created and performed (Bamberg, 2010), as was identified in the five narrative types. For example, narration gave meaning to the process of sorting out how participants were the same person but different, highlighting the contradictory and non-dichotomous nature of identity formation and meaning creation.

Despite the contradictions found in identity narratives, unpacking meaning remained the foundation of this study. This study drew on the thoughts of McAdams (2006) who wrote, "people seek meaning in their lives – a meaning that transcends any particular situation" (p. 102). Identity narratives do not always make sense but they are always purposeful to the teller. Just as a storyteller incorporates new events and experiences in the story, the narrative includes new meaning. What does living with a spinal cord injury mean now, 10 years later or 20 years later? What does not being able to finish school because of health related issues mean now as opposed to then? What does becoming a mother mean despite the uncertainty? It was meaning as shared through narration that defined these stories and ultimately one's identity.

### **Grounding Identity Through Narration**

Narration of self following a spinal cord injury provided an opportunity for identity construction grounded in experience. Participants could speak about their reality without being considered right or wrong, or without having their story deciphered to determine validity or truth. Participants spoke about their experience as lived and recalled. They were given the chance to reflect on self pre and post injury

with the understanding that each time they told the story, their reflections would be different. The meaning might change, along with how they articulated and understood themselves pre and post self. One individual said, *"If you were to ask me the same question tomorrow, my answer would probably be different."* This fluidity could certainly impact analysis, in that the experiences have the potential to be narrated differently depending on context, time and circumstance, which in turn influences reality. There was no correct formula for narrating self, just as there was no right way to create self. Identity was grounded in their lived experience, narrated in response to the question and influenced by numerous factors from relationships to personal self.

### **The Transforming Self**

#### **Identity is Dynamic**

By studying the transition of self post-injury, I learned first and foremost that identity is both stable and fluid. The storying of human experiences highlighted the dynamic process that enveloped self, especially after a forced identity transition. Pals (2006) wrote that difficult experiences can challenge the story that has been providing coherence, meaning and purpose. In this study, the narrators integrated self at each stage, in evolving stories that spoke of challenge and perseverance, chaos and stability, old and new. They organized events and identities in narratives that made sense for them at that moment. Based on this, I have discovered that "identities are not fixed or frozen" (McAdams et al., 2006, p. 7). Rather, identities are subject to the

barrage of constant change of context, activity, or progress. According to McAdams et al. (2006), we know that, "identity is expected to change with age and with changing circumstance" (p. 7), creating dynamic identities in response to context. However, this does not mean that identity was void of stability. To the contrary, there was a layer of stability that existed between pre self and post self where similar stories provided continuity (e.g., family, relationships, interests, hopes, achievements, etc.), helping individuals narrate their way through transition.

### **(Trans)Formation of Identity in Transition**

I discovered that self can be recreated in transition, with the understanding that the transition was never complete for persons with SCI. I discovered that people have an amazing ability to reconstruct self while dealing with difficult circumstances. Participants expressed what it was that they are living through while figuring out where they are going. This was evident in the Change and Rehabilitation Narratives. Through the telling of stories these individuals shared with me who they were, both with and without the injury, family, and sometimes (un)certainty. As narrators, they expressed the different aspects of self at different points on their journey, indicating that self can be recreated in transition. Narration helped participants make sense of what was happening, as well as who they would become.

Like identity narratives, the transition of living with a spinal cord injury was never complete. Every time a new challenge arose, transition was occurring. For example, pain as a result of a spinal cord injury was often a reminder of what was,

triggering aspects of self that were dormant and “dealt with.” Self may be questioned as the individual tried to find meaning by narrating new experiences. Such was the case with Destiny when she became a mother. As shared by Taylor and Jeremiah, frustrations with health concerns caused them to re-evaluate their physical self, which resulted in revisiting and negotiating other aspects of self as well, such as their social identities, education, future, etc. Narration, identity, identity narratives and transition are all subject to what one narrator called “*crests and waves*,” the unpredictability of changing circumstances and contexts.

#### **Different Narration. Similar Circumstance.**

After listening to these six individuals narrate their experiences, I recognized that there were differences in identity narratives despite similar forced identity transitions as a result of SCI. Just as people tried to navigate between sameness and difference post injury, I noticed both a sameness and difference in how people transitioned, dealt with, embraced and understood life after a spinal cord injury. While each individual experienced a spinal cord injury, not everyone described the SCI as transformative. While the SCI was life changing, it was not always welcomed change. While the SCI built and strengthened relationships, they were not always the relationships they had prior to the injury. For some, their narrations were unique despite a common experience, as was seen in the rehabilitation experiences shared by Nigel, Taylor and Jeremiah.

I discovered that part of reconstructing identity was attempting to reconstruct self in terms of social group. For example, distinct injury classification affected what peer groups people belonged to, their relationships with their family and friends (e.g., the “helpful” child), sports teams they were a part of, and social groups (e.g., dancing) they participated in. This had a tremendous impact on self post-injury, where there was a transition from *I am this to I am that* (e.g., able bodied to paraplegic). However, all aspects of self went through a process of integration, differentiation, and negotiation post-SCI, resulting in differences in identity narratives. For McAdams (2006), each storyteller continues to make sense of their lives through the stories they share, stories that are grounded in individual experiences, challenges, and transitions. I was not surprised by the fact that despite similar circumstance, differences abounded. Support, relationships, resilience, hope, faith and so on - all influenced transition, which ended up playing a critical role in how participants chose to narrate their experience. In the wake of such similar circumstances distinct selves were formed.

### **Implications of Narrative and Identity Research**

This study has several implications for social work practice. First, this study can have implications for individuals who encounter moments of shifting identities while attempting to create new self. Second, the study shows the usefulness of narration in adjustment and transition work. Lastly, the study illustrates the influence and power of the social worker in the co-construction (narration) of stories post injury.

### **Drawing Attention to Fluidity**

This study offered the opportunity to understand the stability and fluidity of identity in terms of transition. Whether we work with persons who have lost a loved one, experienced divorce, have been diagnosed with cancer or have experienced any other type of forced transition, we can understand that they will be both maintaining and changing themselves as they try to comprehend and attach meaning to what it is they are living through. We need to be mindful of the narratives they are sharing so that we might recognize these identity transitions (e.g., married to 'widowed,' married to single, healthy to ill to cancer free, etc.) and apply appropriate methods. We cannot get stuck in techniques that stifle the individual's growth and development or approaches that dismiss or diminish the experiences of the storyteller. This requires us to be good listeners, not good authors, which brings me to the next practice consequence.

### **Narration in Practice**

This study showed the usefulness of narration in social work practice. For people struggling with transition and trying to explain what it is they are experiencing, narration can be a method to evoke intimate conversation. Telling stories allows the narrator to communicate what is significant and what matters (Mattingly & Garro, 2000). Narrative also offers powerful insight into what gives life meaning. These stories can be compelling, offering a different perspective that challenges practitioners to respond effectively. When referring to illness, Rosaldo (1963) as quoted in Mattingly

and Garro (2000, p. 15) stated, "narratives often reveal more about what can make life worth living than about how it is routinely lived" (p. 2). As such, narratives have the potential to provide interventions that are more individualized.

Furthermore, inviting someone to *share their story* was an invitation like none other. It was personal. It was clear. It allowed the individual to choose and decide what they wanted to share. The stories provided insight into underlying ideologies, practices as well as social, personal, and cultural expectations that may influence adjustment and transition (Mattingly & Garro, 2000). Narration also provides an opportunity for critical reflection and engagement with the individual on a very personal level. We are offered the opportunity to delve deeper into meaning, purpose, aspects of self that still remain despite the transition, as well as aspects of self that will never be the same.

We can also see how individuals move through time. For example, we can explore how events and experiences are constructed through social interactions, power, access, dominant discourses and roles (Mattingly & Garro, 2000). Narration becomes an interpretative practice, engaging the individual and the practitioner. However, with narration comes the issue of co-authorship, which requires reflexivity, a conscious, personal reflection on power and influence, adhering to the ethical considerations of narrative work. A reflexive stance also means that we have a higher level of self-awareness and overall awareness of the person, the social spaces in which

knowledge is produced, the location of the practitioner and complex process of unpacking said knowledge.

### **The Practitioner Influence in Co-construction**

The audience (the practitioner) plays a vital role in narrative development, through the questions we ask and our assumptions, as well as verbal cues and physical presence. There was a complex negotiation between teller and listener that demanded constant attention and reflection to insure that the teller's story was not influenced or motivated by professional presence (Mattingly & Garro, 2000). Ultimately, our role is to become witnesses to the telling of personal stories and we should recognize this role as both a privilege and challenge so that we do not fool ourselves into thinking we are objective participants. This requires a level of vigilance to ensure that stories are not reframed in accordance to our views, principles and expectations.

Part of my task as researcher was learning how to listen *for* stories, rather than listening *to* stories. For example, I acknowledge that I was not a neutral agent. My approach to interviewing and the questions selection was influenced by hidden assumptions, for which I needed to be accountable. However, I was transparent and open about my intentions, the purpose of my research and my role as a researcher, which was reflected in my approach to interviewing. I was there to listen *for* stories as they told it and experienced it, anticipating their meaning and interpretation, not seduced by expert knowledge.

### **A Final Note on “What Now?”**

While this study yielded findings that included the narratives of six individuals with SCI, it by no means answered all the questions we may have about the effects of SCI on identity narratives. If anything, it should make us want to find out more. I would hope that these findings inspire us to look deeper into the application of narrative research for other populations who have or are experiencing forced identity transitions. At the same time, we have a great deal more to learn about the intricacies of identity and the role of narrative in identity formation and transformation. For example, it would be beneficial to conduct a longitudinal study of experiences over time, at different points in an individual’s life - 5 years, 10 years, 15 years after injury (or any life changing experience).

Future research may also be beneficial when exploring the link between further narrative reconstruction and meaning-making, to advance our understating of the therapeutic implications. For example, in a therapeutic setting, whether meaning-making was a process or outcome was an important distinction that would have consequences for identity reconstruction and other therapeutic strategies.

### **Summary**

This study aimed to explore the effects of SCI on identity narratives and the role of storytelling following an injury. These questions were answered through the collection and analysis of narratives told by individuals with a spinal cord injury. Five narrative types were revealed within pre, during and post-SCI. The findings suggest

that SCI was indeed a forced identity transition that resulted in identity narratives that linked pre-self and post-self, giving the teller's experiences meaning. Identity narratives also provided an outlet for self-expression, as stories were formed and transformed. Lastly, these identity narratives showed that self can be recreated in transition. Like the participants, their stories were dynamic, constantly subject to (re)construction. However, when all is said and done, stories can be the reset button for many, or as Taylor so aptly put it, life before injury was "*just kinda plain vanilla,*" but after the SCI, "*I had the chance to make it extraordinary.*" Stories are indeed extraordinary.

## Bibliography

- Alder, P., & Alder, P. (2012). In S. E. Baker, & R. Edwards (Eds.), *How Many Qualitative Interviews is enough?: Expert Voices and early career reflections on sampling and cases in qualitative research*, (pp. 8-11). National Centre for Research Methods: Economic and Social Research Council.
- Bach, C. A., & McDaniel, R. W. (1993). Quality of life in quadriplegic adults: A focus group study. *Rehabilitation Nursing, 18*(6), 364-366.
- Bamberg, M. (2004). Narrative discourse and identities. In J. C. Meister, T. Kindt, W. Schernus, and M. Stein (Eds.), *Narratology Beyond Literary Criticism*, (pp. 213-237). New York, NY: Walter de Gruyter. Retrieved from [www.clarke.edu/~mbamberg/Papers/Narrative\\_Discourse\\_and\\_Identities.pdf](http://www.clarke.edu/~mbamberg/Papers/Narrative_Discourse_and_Identities.pdf)
- . (2010). Who am I? Narration and its contribution to self and identity. *Theory and Psychology, 21*(1), 1-22. doi:10.1177/0959354309355852.
- Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: A sociological introduction*. Malden, MA: Blackwell.
- Bell, A. (2003). A narrative approach to research. *Canadian Journal of Environmental Education 8*, 95-110.
- Berger, P. L., & Luckmann, T. (1971). *The social construction of reality*. London, UK: Penguin.
- Bernard, R. H. (2006). *Research methods in anthropology: Qualitative and quantitative approaches* (4th ed.). Altamira Press.
- Bruner, J. (1986). *Actual Minds, Possible Worlds*. Cambridge, MA: Harvard University Press.
- Bruzuzy, S. (1997). Deconstructing disability: The impact of definition. *Journal of Poverty, 1*(1), 81-91.
- Cairns, D., & Baker, J. (1993). Adjustment to spinal cord injury. A review of coping styles. *The Journal of Rehabilitation 59*(4), 30(34).
- Campbell, F. (2009). *Contours of ableism: The production of disability and abledness*. UK: Palgrave Macmillan.

- Canadian Paraplegic Association (Nova Scotia). (2013). *Spinal cord injuries (SCI)*. Retrieved from [www.thespine.ca](http://www.thespine.ca)
- Carcary, M. (2009). The research audit trail: Enhancing trustworthiness in qualitative inquiry. *The Electronic Journal of Business Research Methods* 7(1), 11-24. ISSN 1477-7029
- Clandinin, D. J. (2007). *Handbook of narrative inquiry: Mapping a methodology*. Thousand Oaks, Ca.: Sage.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative Inquiry*. San Francisco, CA: Jossey-Bass
- Clandinin, D. J.. and Huber, J. (2010). Narrative inquiry. In B. McGraw, E. Barker, and P. Peterson (Eds.), *International encyclopedia of education* (3rd ed.), (pp. 1-26). New York, NY: Elsevier.
- Connelly, F. M., & Clandinin, D. J. (1990). Stories of experience and narrative inquiry. *Educational Researcher* 19(4), 2-15.
- and Clandinin, D. J., (2006). Narrative inquiry. In J. Green, G. Camilli and P. Elmore (Eds.), *Handbook of complementary methods in education research*, (pp. 375-385). Mahwah, NJ: Lawrence Erlbaum.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, Ca.: Sage.
- Devlin, R., & Pothier, D. (2005). Introduction: Towards critical theory of dis-citizenship. In R. Devlin and D. Pothier (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law*. Vancouver, BC: Colombia Press.
- Dorsett, P. (2001) *Spinal cord injury: How do people cope?* Queensland, AU: School of Social Work.
- Dunn, D. S., & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology*, 58 (2), 148-157.
- Engle, D. M., & Munger, F. W. (2007) Narrative, disability and identity. *Narrative*, 15(1), 85-94. Retrieved from <http://www.jstor.org/stable/20107406>

- Erikson, E. H. (1993) [1950]. *Childhood and Society*. New York, NY: W. W. Norton & Company.
- Fook, J. (2002). *Social work: Critical theory and practice*. Washington, DC: Sage Publications.
- Freeman, M. (2000). When the story's over: Narrative foreclosure and the possibility of self-renewal. In M. Andrews (Ed.), *Lines of Narrative: Psychosocial Perspectives* (pp. 81-91). London, GBR: Routledge.
- Frank, A. (1997). *The wounded storyteller: Body, illness and ethics*. Chicago, IL: The University of Chicago Press.
- Gergen, K. (1991). *The saturated self: Dilemmas of identity in contemporary life*. USA: Basic Books.
- Gilson, S. F., & DePoy, E. (2002). Theoretical approaches to disability content in social work education. *Journal of Social Work Education*, 38(1) 153-165.
- Giovannoli, R. (2013). *The narrative method of inquiry: Second candidacy essay*. Retrieved from [www.sonic.net/~rgiovan/essay.2.PDF](http://www.sonic.net/~rgiovan/essay.2.PDF)
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.
- Guidano, V. (1987). *Complexity of the self: A developmental approach to psychopathology and therapy*. New York, NY: The Guilford Press.
- Hertz, R. (1997). *Reflexivity and voice*. London, UK: Sage Publications.
- Herz, M., & Johansson, T. (2011). Critical social work: Considerations and suggestions. *Critical Social Work*, 12(1), 28-45.
- Hiranandani, V. (2005). Towards a critical theory of disability in social work. *Critical Social Work* 6(1). Retrieved from [www1.uwindsor.ca/criticalsocialwork/towards-a-critical-theory-of-disability-in-social-work](http://www1.uwindsor.ca/criticalsocialwork/towards-a-critical-theory-of-disability-in-social-work)
- Hosking, D. (2008). *Critical disability theory: A paper presented at the 4th biennial disability studies conference*. Lancaster, UK: Lancaster University.

- Hunter, S. (2010). Analysing and representing narrative data: The long and winding road. *Current Narratives*, 1(2), 44-54. Retrieved from <http://ro.uow.edu.au/currentnarratives/vol11/iss2/5>
- Josselson, R. & Lieblich, A. (Eds.) (1999). *The narrative study of lives*. Newbury Park, CA: Sage Publications.
- . (1996). *Ethics and Process in the Narrative Study of Lives*. London, UK: Sage Publications, Inc.
- Jovchelovitch, S., & Bauer, M. (2000). Narrative interviewing. [online]. London: LSE Research Online. Retrieved from <http://eprints.lse.ac.uk/2633>
- Klein, R. (2011). *The course manual: SWLK 6413*. St. John's: Memorial University of Newfoundland.
- Kramp, M. K. (2004). Exploring life and experience through narrative inquiry. In K. deMarrais, & S. D. Lapan. (Eds.), *Foundations for Research: Methods of Inquiry in Education and the Social Sciences*, (pp. 103-122). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Larsson, S., & Sjoblom, Y. (2009). Perspectives on narrative methods in social work research. *International Journal of Social Welfare*, 19, 272-280. doi: 10.1111/j.1468-2397.2009.00672.x
- Lieblich, A. Tuval-Mashiach, R., and Zilber, T. (1998). *Narrative research: Reading, analysis, and interpretation* (Vol. 47). Thousand Oaks, CA: Sage Publications.
- Lohne, V. (2007). The incomprehensible injury - interpretations of patients' narratives concerning experiences with acute and dramatic spinal cord injury. *Scand J Caring Sci*, 23, 67-75. doi: 10.1111/j.1471-6712.2007.00591.x\
- Labov, W. (1982). Speech actions and reactions in personal narrative. In D. Tannen (ed.), *Analyzing discourse: Text and talk* (pp. 219-247). Washington, DC: Georgetown Press.
- Mattingly, C., & Garro, L. (2000). *Narrative and cultural construction of illness and healing*. London, England: University of California Press.

- May, G. E. (2005). Changing the future of disability: The disability discrimination model. In G. E. May & M. B. Raske (Eds.), *Ending disability discrimination: Strategies for social workers* (pp. 82-98). Boston: Pearson Education, Allyn & Bacon.
- McAdams, D. P. (2011). Narrative identity. In S. J. Schwartz, K. Luyckx, & V. L. Vignoles (Eds.), *Handbook of Identity Theory and Research*, (pp. 99-115). New York: Springer Science+Business Media, LLC. doi:10.1007/978-1-4419-7988-9\_5.
- , Josselson, R., & Lieblich, A. (2006). Introduction. In D. P. McAdams, R. Josselson & A. Lieblich (Eds.), *Identity and story: Creating self in narrative*, (pp. 3-11). Washington, DC: American Psychological Press.
- (1993). *Stories we live by: Personal myths and the making of the self*. New York, NY: Morrow.
- Mullaly, B. (2010). *Challenging oppression and confronting privilege* 2nd edition. Toronto: Oxford University Press.
- Pals, J. (2006). Narrative identity processing of difficult life experiences: Pathways of personality development and positive self transformation in adulthood. *Journal of Personality*, 74, 1079-1109. doi: 10.1111.j.1467-6494.2006.00403.x
- Pfeiffer, D. (2001). The conceptualization of disability. In S. N. Barnartt & B. M. Altman (Eds.), *Exploring theories and expanding methodologies: Where we are and where we need to go* (pp. 29-52). New York: Elsevier Science.
- Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. In J. Amos Hatch and Richard Wisniewski (Eds.), *Life history and narrative* (pp. 5-23). London: Falmer Press.
- (1988). *Narrative knowing and the human sciences*. Albany: State University of New York Press.
- Porter Abbott, H. (2008). *The Cambridge introduction to narrative: Cambridge introductions to literature*. Cambridge University Press.
- Pedro, S. (2010). *Women, sport and spinal cord injury: Narrative and resilience* (Unpublished thesis). Exeter University.

- Ricoeur, P. (1991). Narrative identity. *Philosophy Today*, 12, 73-8.
- Riessman, C. K. (2012). Analysis of personal narratives. In J. Gubrium, J. Holstein, A. Marvasti, and K. McKinney (Eds.), *The SAGE Handbook of Interview Research: The Complexity of the Craft*, (pp. 367-380). Los Angeles, CA: Sage Publications.
- (2008). *Narrative methods in human sciences*. Thousand Oaks, Ca.: Sage.
- (2005). Narrative analysis. In N. Kelly, C. Horrocks, K. Milnes, B. Roberts, and D. Robinson (Eds.), *Narrative Memory & Everyday Life* (pp. 1-7). Huddersfield: University of Huddersfield.
- (2002). Analysis of personal narratives. In J. Gubrium & J. Holstein. (Eds.), *Handbook of Interview Research: Context and Method* (pp. 695-710). London, UK: Sage Publications, Inc.
- (1990). *Divorce talk: Women and men make sense of personal relationships*. New Brunswick, NJ: Rutgers University.
- (1993) *Narrative analysis* (Qualitative Research Methods Series 30). Sage, Newbury Park, CA.
- , & Quinney, L. (2005). Narrative in social work: A critical review. *Qualitative Social Work* 4(4), 391-412.
- Riley, T., & Hawe, P. (2005). Researching practice: the methodological case for narrative inquiry. *Health Education Research* 20(2), 226-236.
- Roscoe, K.D. & Madoc, I. (2009). Critical social work practice a narrative approach. *International Journal of Narrative Practice*, 1, 9-18.
- , Carson, A. M. and Madoc-Jones, I. (2011). Narrative Social Work: Conversations between theory and practice. *Journal of Social Work Practice*, 25(1),47-61
- Rosenstiel, M. A., & Roth, S. (1981). Relationship between cognitive activity and adjustment in four spinal cord injured individuals: A longitudinal study. *Journal of Human Stress*, 7(1), 35-43.
- Ryan, Anne B. (2002). *How was it for you? Learning from couples' experiences of the first years of marriage*. Dublin, Ireland: NP.

- Ryan, Anne B. (2006) *Methodology: Analysing qualitative data and writing up your findings*. In *Researching and Writing your thesis: a guide for postgraduate students* (pp. 92-108). Mace: Maynooth Adult and Community Education.
- Sandelowski, M. (1991). Telling stories: Narrative approaches in qualitative research. *Journal of Nursing Scholarship*, 23(2), 161-166.
- Scott, S. B. (1997). *Lives in transition: The experience of living with a spinal cord injury and the meaning of adjustment*. (Unpublished thesis). University of British Columbia: Department of Counselling Psychology
- Sparkes, A. C., & Smith, B. (2005). When narratives matter: men, sport, and spinal cord injury. *Journal of Medical Ethics*, 31, 81-88. doi:10.1136/jmh.2005.000203
- Titchkosky, T. (2003). *Disability, self and society*. Toronto, ON: University of Toronto Press.
- Trahar, S. (2009). Beyond the story itself: Narrative inquiry and autoethnography in intercultural research in higher education. *Qualitative Social Research*, 10(1), 1-16.
- Valvano, A. K. (2012). *Traumatic injury and identity: Incorporating traumatic episodes into life story*. (Doctoral dissertation). Retrieved from e- Publication@Marquette, [http://epublications.marquette.edu/dissertations\\_mu/214](http://epublications.marquette.edu/dissertations_mu/214). (214)
- Vignoles, V. L. (2011). Identity motives. In S.J. Schwartz, K. Luyckx, & V. L. Vignoles (Eds.), *Handbook of Identity Theory and Research*, (pp. 403-425). New York: Springer Science+Business Media, LLC. doi:10.1007/978-1-4419-7988-9\_18.
- Vignoles, V. L. Schwartz, S., & Luyckx, K. (2011). Introduction: Towards an integrative view of identity. In S.J. Schwartz, K. Luyckx, & V. L. Vignoles(Eds.), *Handbook of Identity Theory and Research*, (pp. 1-27). New York: Springer Science+Business Media, LLC.
- Wosket, V. (1999). *Therapeutic Use of Self: Counselling Practice, Research and Supervision*. London, UK: Routledge.
- Yoshida, K. (1993). Reshaping self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health and Illness*, 15(2), 217-245. ISSN 0141-9889

## Appendix A

### TELEPHONE SCRIPT FOR RECRUITMENT

*A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives  
Master of Social Work, School of Social Work  
Memorial University*

Hello.

May I speak with \_\_\_\_\_?

This is Darrell Robar from the Canadian Paraplegic Association (Nova Scotia). I am calling to see if you would be interested in participating in an upcoming research project on spinal cord injury. You will be given the opportunity to share your experiences about this transition, living with an SCI, and discuss its effect on your sense of self.

Continue, depending on answer... If yes,

You will get to share your story with Lorna Griffin-Fillier, a Master of Social Work student at Memorial University and social worker experienced in spinal cord injury.

Before I continue, would you mind answering a few questions, just to make sure you are a suitable participant for this study? If yes,

1. Have you sustained a spinal cord injury?
2. Did you consider it to be a life altering experience?
3. Did you experience spinal cord injury as a forced transition, in that you neither desired nor initiated the change?
4. Did sustaining a spinal cord injury pose challenges?
5. Is the period of transition still accessible and fresh in your memory, yet sufficient time has elapsed such that you have had opportunity for reflection?
6. You have not been a client of or received services from Lorna Griffin-Fillier?

You have answered all the questions and are eligible to participate. If you are interested becoming a participant or would like further details about the study, please contact Lorna at 902-423-1277 Ext 105 or by email [w99ljg@mun.ca](mailto:w99ljg@mun.ca).

Thank you for your time.

## Appendix B

### CONFIDENTIALITY AGREEMENT

(for Transcribers, Supervisors and Mr. Darrell Robar, Recruitment Assistant)

**Title:** A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives

**Researcher:** Lorna Griffin-Fillier  
Master Student - School of Social Work  
1880 Waverley Rd  
Waverley, NS B2R 1Y5  
Ph: 902-423-1277 Ext 105  
Fx: 902-492-1213  
[w99ljg@mun.ca](mailto:w99ljg@mun.ca)

In the course of your involvement in this research project as a transcriber or supervisor, you are expected to maintain confidentiality regarding any information you may learn about the participants in this study. Any identifying information pertaining to the research participants shall not be shared with anyone outside of the researcher (Lorna Griffin-Fillier) and those who are likewise involved in the project and who have also signed a confidentiality form.

I \_\_\_\_\_ have read the above confidentiality agreement and agree to abide by the principles and practices contained in it.

\_\_\_\_\_  
Signature Date

\_\_\_\_\_  
Witness Date

## Appendix C

### INFORMATION SHEET FOR POTENTIAL STUDY PARTICIPANTS

*A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives*  
*Master of Social Work, School of Social Work*  
*Memorial University*

My name is Lorna Griffin-Fillier. I am enrolled in the Master of Social Work Program at the School of Social Work at Memorial University. I am currently undertaking a study of narrative, identity and transition post spinal cord injury.

#### **Clarification of Terms**

The term *narrative* refers to the stories we tell about our life experiences that represent what we know and how we choose to communicate it.

A *transition* refers to the process that occurs after sustaining a spinal cord injury.

*Identity* refers to how you see yourself, which encompasses individuality and personal identity. It can also include the process of creating identity that is how people develop a distinct personality.

#### **Examples of Suitable Participants**

Individuals who:

- have sustained a spinal cord injury and considered it to be a life altering experience

#### **Sample Criteria**

In order to participate in the study, you must meet the following criteria:

- You are a person with a spinal cord injury
- You feel comfortable sharing your experiences detailing life before and after injury
- The spinal cord injury was the result of a forced transition, meaning that it did not occur over an extended period of time but was abrupt and sudden
- The spinal cord injury presented various challenges and was considered momentous
- The period of transition is still fresh in your memory, yet sufficient time has passed such that you have had opportunity for reflection on those experiences
- You have not received direct counselling services from Lorna Griffin-Fillier

## **Nature of Involvement**

You will be asked to participate in one audio-recorded interview, which will be 1 - 2 hours in length. The interview will focus primarily on living with a spinal cord injury, where I will ask you questions about life before sustaining a spinal cord injury and life after the spinal cord injury. You will be given the opportunity to talk about your current understandings of self, how that differs from pre-injury and to what effect, as well as the circumstances leading up to injury and factors that hindered or supported the transitioning process.

## **Purpose of Research**

The results of this study will assist social workers to understand the realities of living with a spinal cord injury, improving their ability to offer assistance to individuals who have sustained a spinal cord injury who may be having difficulty with the transition. Also, increased knowledge of the experiences of persons with spinal cord injury will be useful for social workers in therapeutic settings who are working with individuals who are wrestling with adjustment post spinal cord injury. Likewise, the insights gained from this study may be useful to any individual or group, who cares about the emotional well-being of individuals going through a major identity transition, associated with a spinal cord injury or forced transitions, and are eager to lend their well meaning and informed support.

## **Process**

If you meet the sample criteria and are interested in participating or learning more about the study you can contact me using the following contact information:

Lorna Griffin-Fillier  
Master Student - School of Social Work  
1880 Waverley Rd  
Waverley, NS B2R 1Y5  
Ph: 902-423-1277 Ext 105  
Fx: 902-492-1213  
[w99ljg@mun.ca](mailto:w99ljg@mun.ca)

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found in compliance with Memorial University's ethics policy. If you have ethical concerns about this research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at [icerh@mun.ca](mailto:icerh@mun.ca) or by telephone at 709-864-2861.

## Appendix D

### INFORMED CONSENT STATEMENT

Title: A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives

Researcher: Lorna Griffin-Fillier  
Master of Social Work - School of Social Work  
1880 Waverley Rd  
Waverley, NS B2R 1Y5  
Ph: 902-423-1277 Ext 105  
Fx: 902-492-1213  
[w99ljg@mun.ca](mailto:w99ljg@mun.ca)

You are invited to take part in a research project entitled, *A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives*.

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any other information given to you by the researcher.

It is entirely up to you to decide to take part in this research. If you chose not to take part in the research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Introduction:

This research project will be conducted by Lorna Griffin-Fillier, a Master Student at the School of Social Work at Memorial University. This research project will explore the experiences of persons who have sustained a spinal cord injury, through narrative as they describe that transition. The final analysis will use information collected during this research process.

---

Participant's Initials

Purpose:

The purpose of this study is to gain an understanding of identity narratives and transition for persons living with spinal cord injury, and the subjective experiences of individuals such as you, who have been forced to transition as a result of this injury. This investigation will explore, through the sharing of stories, how individuals who have sustained a spinal cord injury have negotiated this transition and the accompanying shifts in their identity and understanding of self.

What you will do in this study:

You will be one of 10-12 individuals participating in this study. Your participation will involve one interview with the researcher. The interview will be digitally audio recorded and will be 1-2 hours in length. The interview will focus primarily on your experiences before and after injury. You will be given the opportunity to talk about your life prior to injury, your experiences following injury, and how you adjusted post injury. You will be able to discuss your current understandings of self, how that differs from pre-injury and to what effect.

You will also have an opportunity to provide reflections separate from the interview, by way of an electronic journal which will be used to record thoughts and experiences that were not shared during the interview. You may keep these journals private or you may choose to share them with the researcher as a secondary form of data collection. This information will be used in the same manner as the data collected via the digitally recorded interviews. Once the study is complete, the researcher will delete their copy of the journal(s). You are free to keep your copy, should you wish to do so.

Participant Withdrawal:

As a voluntary participant, you will be given the opportunity to withdrawal from the study. Each participant will be reminded of their right to withdraw immediately following the interview. This will be your final opportunity to remove yourself from the study. There will be no consequences for the participant and all personal information collected will be destroyed as per appropriate protocol.

---

Participant's Initials

You will not be able to withdraw from the study once the interviews have been transcribed. By then, you would have been given ample time to remove yourself, withdraw or voice disapproval. Once the interviews are complete, the analysis phase begins and it is important that all collected information remain consistent throughout the course of the study. It would be very difficult to extract individual narratives once they have been included in the analysis.

#### Possible Benefits:

You may experience the opportunity to discuss your experiences and have them valued as a benefit. Your contributions will be used to advance social work knowledge and practice and will serve as the basis for subsequent studies and publications. Your contributions may also influence the development of programs that could be helpful to others in similar circumstances to your own.

#### Possible Risks:

Participation in this study will require that you share your experiences with the researcher. You will be asked to reveal your insights and understandings about these experiences. There is a possibility that you may feel uncomfortable speaking about these personal and sensitive matters. At any point you have the right to stop the audio-recorder and/or interview and/or leave the study. You can also refuse to answer any question. The researcher is an experienced social worker and will be monitoring your emotional state and if you become distraught, will seek assurances from you that you are willing to proceed before continuing with the interview. The researcher will also provide you with a list of professionals you could speak to, if the need arises.

#### Confidentiality:

The (digital) audio-recordings will be uploaded onto a mini hard drive that will be stored in a locked cabinet in the researcher's home office. Either the researcher or a professional transcriber, who will have signed a confidentiality form, will transcribe the recordings. Digital recordings sent to the transcriber are done through a security-encrypted email and deleted once the transcription is complete and sent to the researcher. Supervisors involved in the project will sign a confidentiality form. Transcripts, *Informed Consent Statements*, *General Demographic Information Sheet* will also be stored in a locked cabinet in the researcher's home office.

---

Participant's Initials

#### Anonymity:

You will be asked to complete a General Demographic Information Sheet but it will not include your name and will not be linked to your interview data. Identifying information will be removed from all transcripts. Direct quotes may be used to highlight analysis and discussion, and excerpts from the interviews will be used in publications but names and identifying information will be removed or disguised. You will also be given a pseudonym. However, given the specific nature and small size of the sample, an informed reader may be able to identify you as a participant.

#### Recording of Data:

Interviews will be digitally audio-recorded.

#### Reporting of Results:

It is anticipated that the results of this study will be published in a thesis, academic journals and possibly presented at conferences.

#### Storage of Data:

Due to the existence of identifying information and as per the researcher's discretion, digital recordings will be destroyed immediately after the transcripts are completed and checked for errors.

In keeping with Memorial University policy on Integrity in Scholarly Research, the transcripts (with identifying information removed) will be stored in a locked cabinet in the researcher's home office for a minimum of five years following the completion of the analysis, after which they will also be destroyed.

#### Questions:

You are welcome to ask questions at any time during your participation in this research. If you would like more information about this study please contact Lorna Griffin-Fillier RSW, [w99ljg@mun.ca](mailto:w99ljg@mun.ca) , 902-423-1277 Ext 105. You may also contact Dr. Catherine DeBoer at [cdeboer@mun.ca](mailto:cdeboer@mun.ca) or by telephone at 709-864-2554.

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Participant's Initials

Disclosure:

I am the Manager of Client Services and a Rehabilitation Counsellor for the Canadian Paraplegic Association (Nova Scotia). As such, I would like to make clear that I will be interviewing you in a **research capacity only**, separate from my position. This study does not have any connection to or affiliation with CPANS and nor will details of your participation be revealed at any point. It is vital that you are aware of the voluntary nature of your participation and that future services from CPANS will not be affected (directly, indirectly, adversely, etc.) by your decision to or not to participate.

ICEHR Approval Statement:

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about this research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at [icehr@mun.ca](mailto:icehr@mun.ca) or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

You have read the information about the research  
You have been able to ask questions about this study  
You are satisfied with all the answers to your questions  
You understand what this study is about and what you will be doing  
You understand that you will be free to withdraw from the study at any time without having to give a reason, and that doing so will not affect you now or in the future.

If you sign this form, you do not give up your legal rights, and do not release the researcher from their professional responsibilities.

The researcher will give you a copy of this form for your records.

---

Participant's Initials

Your Signature:

I have read and understood the description provided; I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time prior to the transcription process. I consent to having my interviews audio-recorded. I know I can request that the recorder be stopped at any point in the interview. A copy of this Consent Form has been given to me for my records.”

---

Signature of Participant

---

Date

Researcher's Signature:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

---

Signature of Investigator

---

Date

Telephone number: 902-423-1277 Ext 105

E-mail address: [w99ljg@mun.ca](mailto:w99ljg@mun.ca)

## **Appendix E**

### **VERBAL DEBRIEFING STATEMENT**

*A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives  
Master of Social Work, School of Social Work  
Memorial University*

Answering questions of a personal nature can sometimes be uncomfortable. If talking to me today has upset you, or if you have experienced any anxiety, stress, grief, or discomfort or emotional upset as a result of taking part in this study, I would encourage you to seek informal and/or formal support. Please feel free to contact the numbers on the Contact Information for Assistance sheet you have been given. Someone can help you if you want to talk about anything that might have upset you.

If you have any questions about the study itself, you can contact the researcher, Lorna Griffin-Fillier. If you have ethical concerns about this research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at [icehr@mun.ca](mailto:icehr@mun.ca) or by telephone at 709-864-2861. You may also contact Dr. Catherine DeBoer at [cdeboer@mun.ca](mailto:cdeboer@mun.ca) or by telephone at 709-864-2554. These numbers are also on the contact information sheet you have been given.

Thank-you for taking part in the study. I appreciated your time and openness when speaking with me today.

## **Appendix F**

### **CONTACT INFORMATION FOR ASSISTANCE**

*A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives  
Masters of Social Work - School of Social Work  
Memorial University*

**If you need to talk to someone about how you are feeling after sharing your story, you can call:**

Health Link, 24-hour Help Line 811 (In Nova Scotia)

Mental Health Mobile Crisis Team 1-888-429-8167 (toll free)

**If you have any questions about the study, you can call:**

Lorna Griffin-Fillier, Principal Investigator at [w99ljg@mun.ca](mailto:w99ljg@mun.ca) or by telephone at 902-423-1277 Ext 105

**If you have any questions about the way you were treated by the researcher, you can call:**

Chairperson of the ICEHR at [icehr@mun.ca](mailto:icehr@mun.ca) or by telephone at 709-864-2861.

#### **ICEHR Approval Statement:**

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about this research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at [icehr@mun.ca](mailto:icehr@mun.ca) or by telephone at 709-864-2861.

## Appendix G

### GENERAL DEMOGRAPHIC INFORMATION SHEET

*A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives*  
*Master of Social Work - School of Social Work*  
*Memorial University*

1. Numbered Code: \_\_\_\_\_  
(To be assigned by researcher)
2. Age: \_\_\_\_\_
3. Gender: \_\_\_\_\_
4. Classification of Spinal Cord Injury: \_\_\_\_\_
5. Do you identify yourself as a member of an ethnic, cultural or minority group? Yes \_\_\_\_ No \_\_\_\_  
  
If yes, please specify \_\_\_\_\_
6. Country of Birth: \_\_\_\_\_
7. First Language Spoken: \_\_\_\_\_
8. Relationship Status: single \_\_\_\_ married \_\_\_\_ common-law \_\_\_\_ divorced \_\_\_\_  
  
separated \_\_\_\_ widowed \_\_\_\_ partnership \_\_\_\_
9. Do you have children? Yes \_\_\_\_ No \_\_\_\_  
  
If yes, what are the ages and gender of your children?  
\_\_\_\_\_
10. What is your highest level of education? \_\_\_\_\_  
  
Diploma(s) or degree(s) you have earned: \_\_\_\_\_
11. What is your occupation? (If applicable) \_\_\_\_\_

## **Appendix H**

### **INTERVIEW QUESTIONS**

*A Qualitative Study of the Effects of Spinal Cord Injury on Identity Narratives  
Master of Social Work, School of Social Work  
Memorial University*

Two grand tour questions:

Question 1 – Tell me about yourself before the SCI.

Question 2 – tell me about yourself after the SCI.

Possible probing questions:

1. Describe for me the day you sustained a SCI.
2. Describe for me how sustaining a SCI altered the course of your life.
3. Describe for me how you see yourself now.
4. Describe the experience of returning home.
5. Describe what it has been like living with a SCI.