

Acquired Brain Injury and Identity:
Exploring Narrative Shifts Following Involvement in a Multi-Family Outdoor Adventure
Program

by

David Sean Segal
B.A., University of Victoria, 2007

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Abstract

In the aftermath of an acquired brain injury, many survivors and their family members struggle to maintain their preferred identities. This is particularly so given the relational nature of storytelling and the numerous power relations functioning to silence and restrict certain stories, while others are allowed to be told.

This study employs a qualitative methodology, narrative constructionist inquiry, in order to examine the stories of three participants following their involvement in a multi-family outdoor adventure program for brain injury survivors. The aims of the program were to provide opportunities for families to engage in outdoor adventure activities together, such as hiking, sea kayaking and challenge courses, so they could strengthen their relationships with themselves, each other, and their communities.

Through an exploration of their stories, valuable insights regarding the shifts in narrative identity that occurred following brain injury are illuminated. Further, reflections pertaining to the importance of social contexts, nature and adventure, and the value of hope in the construction of preferred identities are discussed. Finally, recommendations for future research and practice are offered.

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Dedication

This thesis is dedicated to Jill, Stan, Terri and Daniel.

Introducing Todd¹: A Father, Spouse, Athlete, and Acquired Brain Injury Survivor

A circle of students quietly and patiently await Todd's presentation. Chairs have been pushed aside, creating space for his electric wheel chair. Todd measures in at over six feet, but is dwarfed by the size of his chair and his slouched position. His voice cracks as he begins to speak. His foot taps in a nervous rhythm against the bottom of his chair. "Over nine years ago I was in an accident playing soccer," Todd begins. "Since the moment my head collided with another person's in an attempt to head a soccer ball, my life has never been the same." I wonder to myself how many times he has told this story in his attempts to piece together what happened on the soccer pitch that day. "I was a good soccer player," he explains. "I also graduated from university, this very institution that I am now speaking at. In fact, I had completed my application for graduate school just prior to my accident."

A palpable tension permeates Todd's story. Prior to his accident Todd was an elite athlete, a supportive and loving father for his young son and spouse for his wife. These stories held an air of sadness. They were ones he knew intimately, yet they had been replaced by a life of relentless struggle towards recovery. The Todd in this room, however, was no longer bound to this identity. Instead, he was here to share the story of his involvement in a unique outdoor adventure program for families experiencing life following an acquired brain injury.

Despite his disclaimer that he was nervous, struggles with anxiety, and does not speak well in front of groups, Todd was a captivating presenter, beautifully sharing his love for his family and his relentless pursuit of recovery with courage and strength. His story provided valuable insights regarding the level of support his family received through their participation in the program. He also demonstrated a profound relationship with hope. Moreover, he provided an opportunity for students to witness his escape from the shackles of his injury and the numerous ways his situation threatened to restrict his preferred identity.

During his presentation, Todd demonstrated he was a dignified human, relentlessly seeking to (re)claim, (re)construct, and (re)discover preferred ways of being in the world. He also demonstrated a rich understanding of the ambiguity and challenges inherent in this process, recounting the numerous moments in which he is positioned as a less than worthy father, husband, and person. Such a tarnished identity was not evident this day. Todd appeared rather as a person deeply concerned with resisting threats to his dignity, a person capable of captivating an audience of undergraduate students and co-presenting important research of which he had intimate knowledge.

As I stood beside Todd, I reflected on the depth to our relationship. I had met him over four years ago while I was a practitioner in the program. I had witnessed his relentless courage and commitment to his family and to himself. I had invited him to be a participant in this research that we were now presenting together. And I was deeply moved and inspired by what was unfolding.

¹ Todd is a participant in this study and decided that he wanted his real name used. All other participant names have been changed to protect their privacy.

CHAPTER 1: INTRODUCTION

"No head injury is too severe to despair of, nor too trivial to ignore."-Hippocrates

Acquired brain injury (ABI) is a serious concern for survivors, their families and communities. According to the World Health Organization (1996), ABI is defined as “damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease. These impairments may be temporary or permanent and cause partial or functional disability or psychosocial difficulties” (as cited in B.C. Brain Injury, 2009, p. 3). This definition has been adopted in the Province of British Columbia (B.C. Brain Injury, 2009).

Although technological advancements have increased our ability to screen for injury, locate precise areas of damage through MRI and neuropsychological testing, and encourage the development of new neural pathways, substantial regeneration of neurons is still a distant dream. Thus, those living with an ABI, their families, and communities are often involved in a lengthy process of recovery long after the initial wounds of the injury have healed. Currently, the majority of attention regarding ABI research and clinical intervention has been devoted to the acute care and management of the injury, primarily from a biological and individual perspective (Yeates, Gracey, & McGrath, 2008). This is despite growing recognition that support is critically needed in the years following the injury, specifically in areas pertaining to psycho-social development (Muenchberger, Kendall, & Neal, 2008) and family-level interventions (Gan, Campbell, Gemeinhardt, & McFadden, 2006).

Previously introduced, Todd is one such person who is struggling to rebuild his

life following a severe brain injury. Similar to many survivors in Canada, Todd has a team of doctors, physiotherapists, occupational therapists, and neuropsychologists supporting his rehabilitation. Also, Todd was one of a few participants who enrolled in a unique multi-family outdoor adventure program² (MFP) offered in Victoria, through the Power To Be Adventure Therapy Society. The program was inspired by family therapist Mary Hendrix whose work with ABI survivors recognized the need to create opportunities for families to be together within a supportive community, yet distanced from their habituated and problem-saturated lives.

The MFP was designed to be a long-term intervention (8 months) and offered monthly program days in conjunction with psycho-education and counselling. It drew on principles from the field of Adventure Therapy (AT), such as challenge and experiential activities to support the attainment of client goals. Moreover, recognition of the importance of contact with nature was a key component of the program design and many of the adventure days occurred within a wilderness setting.

As Todd relates, the program provided him with valuable opportunities to renegotiate his identity and (re)claim, (re)construct, and (re)discover preferred ways of being in the world. For a full description of the program, see Appendix A.

Demonstrated in Todd's story, issues pertaining to identity are emerging from a previously neglected position among rehabilitation professionals and researchers to occupy a pivotal area of concern for survivors (Ben-Yishay, 2008) and their families (Landau & Hissett, 2008). There is now mounting evidence suggesting that in the

² The term "outdoor adventure program" is being used in this thesis to capture a specific combination of group work, outdoor activities, and facilitator guided adventure experiences used to enhance participants' quality of life. It is considered to fall under the broad umbrella of Adventure Therapy practice. A more thorough exploration of the term Adventure Therapy is provided in Chapter 2.

aftermath of ABI, individuals undergo a profound change in their current experience of themselves compared to pre-injury and this can bring forth tremendous discomfort (Ben-Yishay et al., 1985; Myles, 2004; Nochi, 1997). This emerging area in the literature is often referred to as identity loss or disruptions following ABI.

Having worked with Todd and his family, as well as the other families involved in the program, I am intimately aware of the positive shifts in identity that were afforded through their participation. However, the purpose of this thesis is not to evaluate the program or the variables accounting for change. Rather, the curiosity driving this present research surrounds the ways in which program participants and their families (collectively known as survivors), experience the numerous shifts and changes to their identity following an ABI. Thus, the program is not the focus, but instead an important context, indeed the background from which this particular exploration of identity occurs.

By focusing on shifting identities following injury, and in turn the nexus of influences (e.g., available narratives, interpersonal relations, and biographical events) that contribute to particular identity conclusions among participants, attention can be brought to the social and interpersonal dimensions involved in the availability and construction of preferred identities following an ABI. In so doing, this research strives to contribute to a richer understanding of the importance of identity following injury, particularly to the importance of relational processes involved in the reconstruction of identity following such a catastrophic event.

To accomplish these goals, this thesis is divided into five main sections. The first defines key terms and locates myself as researcher in the context of this study. The second is a focused literature review that explores the concept of identity as it pertains to

ABI research and practice. The third is devoted to methodology, in which narrative constructionist inquiry (Sparkes & Smith, 2008) is proposed as a congruent and illuminating method to explore the participants' shifting identities. The fourth consists of the presentation and analysis of three participant stories, while the fifth is a detailed discussion surrounding key points of interest and recommendations for further research.

Definitions of Key Terms

Identity.

This thesis is primarily concerned with the processes involved in identity construction, or how individuals come to identify themselves. Within contemporary social science literature numerous competing definitions of identity exist. According to Styker and Burke (2000), there appear to be two main strands representing divergent points on continuum in which definitions of identity can be classified. One aspect emphasizes the social structural sources of identity (Society), while the second focuses on the internal cognitive processes of identity (Self). Despite considerable variation within and between these categories, strides are being made to uncover the ways they complement and relate to one another.

For the purposes of this study, identity is being theorized from a social constructionist perspective, which arose from social psychology and can be thought to reside more on the social side of the continuum. Specifically, a person's individual identity is thought to be constructed through relational processes, in which the numerous contextual factors (e.g., socio-political, biographical, and cultural) of a person's life serves to constitute their personal sense of identity (Gergen, 1999). From this perspective, there is no separate or fixed identity, nor is there a *personal mind* that resides solely in the

individual (Gergen, 1985). Rather, a person's *individual* identity is thought to be multiple, changing, and emergent from the social and biophysical world they are embedded in. By theorizing identity in such a way, attention is directed to the social and interpersonal dimensions involved in life following ABI. This is an area that has typically garnered less attention than definitions focusing on the internal and cognitive aspects of identity.³

Preferred identity.

The term *preferred identity* is also used throughout this thesis. It can be thought to include life-serving renditions of oneself that retain a personal sense of dignity and hope. The spirit of this definition draws on the work of Cathy Richardson (2004) and Alan Wade (1997), and it emphasizes the importance of preserving and promoting dignity in social life. A more thorough exploration of identity as it applies to ABI research and practice will be covered in the review of the literature.

Narrative identity.

Another key term used in this thesis is that of *narrative identity*. Following the narrative turn in the social sciences, considerable attention has been devoted to exploring the crucial role narratives play in personal meaning-making and the construction of identity (Bruner, 1991; Mahoney, 2003). Yet, the narrative resources available to tell the story of our lives are highly restricted, as the specific *kinds* of narratives available are influenced by contextual factors (for example, cultural scripts or power relations) and as such have a profound influence on how we come to narrate ourselves (Somers, 1994). Thus, narratives become the vehicle through which a relational conception of identity is

³ The researcher recognizes that the definitions of identity provided do not include theories of a deep self, a primordial self, or a transcendent self. Such ideas are fundamentally different conceptualizations of the self and hence not the focus of this particular narrative inquiry.

rendered possible. The term narrative identity, therefore, recognizes the importance of language, contextual factors and the relational processes involved in the construction of identity. A thorough exploration of narrative identity as it pertains to this particular study is presented in the methodology section, Chapter Three.

Discourse.

Finally, it is important to touch on the concept of *discourse* as it relates to identity and to this research in particular. First, discourse is conceptualized as more than linguistic exchanges surrounding a particular topic. Rather, a post-structural comprehension of discourse is employed that acknowledges the ways in which power relations influence language practices, which in turn operate in the production of the social world and the subject (St. Pierre, 2000). From this perspective, “discourse can never be just linguistic since it organizes a way of thinking into a way of acting in the world” (St. Pierre, 2000, p. 485).

Hence, discourse is linguistically and politically oriented. It relates to identity insofar as the stories available to construct particular identities are always embedded within particular power relations, making them more or less accessible and influential. Through narrating ourselves, we enter into the production and reproduction of discourse in the service of identity formation (Davies, 2000). Thus, while the analytic tool in this research is *narrative*, it is important to remember that each narrative examined is responsible for implicating particular discourses in turn; each narrative is therefore a product of existing power relations. A microanalysis of the discourses functioning in the three stories is a different line of inquiry than the one being used in this research. However, the point of discussing discourse is to acknowledge that an examination of narratives always involves discourses, as they are ever present. Moreover, it is to

recognize the discursive nature of identity formation.

Researcher Context

Employing a social constructionist and narrative perspective recognizes the co-constructive basis from which personal and social reality is negotiated and rendered possible (Gergen, 1999). Every act of human meaning making requires a social world in which it is interpreted and made sense of, contributing to an intricate feedback loop. Thus, the “space between” people can be considered as the location of importance from a social constructionist approach (M. Hoskins, personal communication, September 28, 2010).

As the primary investigator in this research, I am aware that my own constructions are ever present. The questions, values, meanings, and curiosities that I brought with me into this research interact with the participants’ stories related during the interview process, making the co-constructed nature of storytelling unavoidable. Thus, had another person replaced me, the dialogues that unfolded would have been different, as well as the lines of inquiry taken in the subsequent analysis and discussion. Therefore, it is important to offer a description of my own context regarding ABI, the place from which I embarked on this research. It is hoped that my perspectives will be made more explicit and that this research can be viewed as a unique and insightful co-creation between the participants and myself. Thus, this section offers a brief description of my experiences as a practitioner working in the area of ABI prior to the commencement of this research.

My first opportunity to work with a community agency serving people with ABI was in the summer of 2000. Apart from my experience of sustaining a mild concussion

while mountain biking in my youth, I had no family members or close friends who had experienced a traumatic brain injury. Thus, my knowledge and understanding of ABI was minimal.

The program was a unique initiative that for five days brought families to a wilderness base camp two hours north of Toronto. What was special about this group, so I was told, was that family members were allowed to accompany their injured member for a week of outdoor adventure activities, such as challenge courses, canoeing, and hiking. This experience helped me to recognize the importance of family work, as it pertains to serving individuals with ABI. I was also introduced to some of the challenges that survivors encounter following injury; memory loss, impulsivity, difficulty with concentration, physical disability, anger outbursts, and heightened family stress are noteworthy ones that stand out for me. I remember the precarious relationship with hope that many families were having due to the magnitude and seemingly insurmountable nature of their problems. I also remember the cathartic joy and irrepressible sense of fun as families stepped aside from their problems and spent time with a supportive group in nature, while canoeing, hiking, and sitting around a campfire. Although this program was only five days in length, it had a profound impact on my perceptions of ABI. In particular, I was exposed to the vast diversity of experiences, as well as the frustration that many survivors experienced due to the lack of services available for their families. I also became aware of the potential for positive changes afforded by being in a supportive group, distanced from their problems, while spending time playing outdoors in nature.

My next practice experience was at a group home in Victoria B.C. that provided long-term residential care for people who had sustained a severe ABI. This was an eye-

opening experience, as these people were living away from their families and many had serious physical limitations preventing them from living their desired lives. Isolation and boredom were common experiences amongst the residents and a constant search for meaning was apparent. Many could no longer participate fully in life and this was accompanied by great sadness. My job involved assisting these individuals in accessing community recreation opportunities and engaging in enjoyable activities. This experience reminded me of the important connections between who we are, what we do, and who surrounds us. The residents' experiences of gardening, swimming, going to concerts, and movies provided rich experiences to initiate conversations back at their group home. I noticed how people would light up when they were able to spend time both doing activities they enjoyed and sharing these experiences with other community members.

Working in the group home also exposed me to some of the dominant medical discourses surrounding ABI. I recall reviewing lengthy neuropsychological reports describing damaged cortical areas and the resultant disabilities. I was told that many of the residents suffered from highly compromised executive functions, entailing poor organization skills, impulsivity, and personality changes. I remember this language being used readily by the staff and clients. The main permeating message was that recovery is a tremendously slow process and in many cases is not possible. Rather, attention should be directed to finding what their strengths are given their *new selves* and abilities. At the time I was not able to articulate or pinpoint my discomfort with these ideas. In retrospect, it was the contrast between my group home experience and my experiences in Ontario, where family work was pursued and the knowledge of the participants was valued to the same degree as medical knowledge.

Undoubtedly, these differing experiences have shaped my understanding of life following ABI. They highlighted the importance of incorporating family into rehabilitation programs, utilizing adventure, nature, and specifically, activities that survivors love doing. Further, they focused my attention on the importance of people's personal meaning-making processes with regard to their injury and how important identity is to recovery.

My most recent work experience began in 2004 when I joined Power To Be Adventure Therapy Society (Power To Be) as a practitioner in the MFP. This non-profit charity incorporates many of the insights mentioned above into their programs and explains why I was so drawn to a multi-family, outdoor adventure approach. In addition, my experiences with Power To Be help to make sense of the frustration I experienced when encountering dominant discourses of brain injury and rehabilitation that focus primarily on the individual and their brain, ignoring their meaning-making processes and social context. I am not denying that the biological aspects of ABI are a critical aspect of ABI research and practice. Clearly the advancements in neuroplasticity for example demonstrate its significance. Rather, I recognize the importance for holistic approaches that considers individuals as meaning-making, spiritual beings, embedded within a web of relationships encompassing more than just their brains. Thus, it was from a desire for integrative thinking surrounding ABI, coupled with my own work experiences that lead me to this study on identity and ABI within the context of a multi-family outdoor adventure program.

Purpose of this Research

In summary, the purpose of this research is to explore the importance of identity construction in the aftermath of an ABI for three participants who recently completed a multi-family outdoor adventure program. Attention is focused on the shifts in their narrative identity and the social processes of identity construction are emphasized. Using such an approach, this research hopes to illuminate the life stories of survivors and move beyond restricted and categorical definitions such as *brain injured person*, and *caregiver*. Finally, an interest regarding how participants' identities shift toward preferred stories in the context of a multi-family outdoor adventure program is pursued.

CHAPTER 2: LITERATURE REVIEW

This chapter introduces the reader to the literature surrounding acquired brain injury (ABI), identity, and the diverse field of adventure therapy (AT). Specifically, the following areas are explored: (a) an overview of ABI, (b) dominant perceptions of identity from rehabilitation professionals, (c) identity as a crucial component of ABI, (d) ABI and identity from a narrative and social perspective, and (e) ABI and AT. Moreover, the guiding research question pertinent to this thesis will be presented and discussed in relation to the above literature.

Acquired Brain Injury

ABI is highly idiosyncratic and involves changes to biological, cognitive, emotive, and social functioning, ranging in severity depending on the extent and location of injury, age, premorbid personality, and individual social circumstances such as family support or access to rehabilitation services (Lezak, Howieson, Loring, Hannay, & Fischer, 2004). As of 2007, approximately 160,000 British Columbians were living with the impacts of acquired brain injury and 14,000 people in the province were expected to acquire new brain injuries by the end of that year (B.C. Brain Injury, 2009).

ABI is the most common cause of brain damage in children and young adults, with most accidents occurring between ages 15 and 24, and high incidence rates in the first five years and for the elderly (Lezak et al., 2004). Falls account for half of all injuries for young children and the elderly, and motor vehicle accidents account for more

than half of all brain injuries in other age groups (Lezak et al., 2004). Mild ABI⁴ makes up the majority of cases, with moderate cases accounting for 8% to 10% and severe cases accounting for fewer than 10%. Although the severe and moderate categories make up a relatively small percentage, these groups represent a major and growing social concern because their rehabilitation needs are so great and so costly, because so few return to fully independent living, and because their disabilities can create severe financial and emotional difficulties for their families (Lezak et al., 2004). Potential changes following ABI are presented in Table 1.

Table 1. Potential changes following ABI

Physical	Cognitive	Behavioural
<p><i>Sensory/perceptual:</i> Double vision Photophobia Dizziness Deafness and/or tinnitus Headache Vision impairment</p> <p><i>Motor:</i> Decreased coordination of movements Ataxia Involuntary eye-movement Paralysis Weakness Numbness</p> <p><i>Structural:</i> Limb shortening Weight gain Muscle atrophy</p>	Slowed reaction time Slowed processing Concentration problems Memory problems Difficulty with retrieval of information Confusion Disorientation Difficulty thinking clearly Compromised spatial learning Compromised executive functions	Heightened distractibility Difficulty multi-tasking Emotional distress Fatigue Automatic activities become effortful Heightened irritability Mood changes Sleep disturbances Low self-confidence Diminished initiative Affective flattening Impulsivity Planning ability and automatic self-monitoring are frequently compromised Diminished or heightened sexual desire Social isolation Empathy and self-reflective or self-critical attitudes greatly diminished Impaired capacity for self-control Unpredictable behaviour Lowered self-awareness

(Note: Adapted from Lezak et al., 2004).

⁴ Estimates of severity of acquired brain injury are often determined by the length of post-traumatic amnesia duration, which is the state of altered consciousness and memory loss following injury: 5-60 minutes is considered mild, 1-24 hours is moderate, and 1-7 days is considered severe (Lezak et al., 2004).

Not surprisingly, life for survivors and their families following acquired brain injury is often accompanied by tremendous physical, emotional, and psychosocial difficulties. Upon returning home from in-patient rehabilitation, many struggle to maintain their intimate relationships (Condeluci, Ferris, & Bogdan, 1992), come to terms with their injuries (Corrigan, Bogner, & Mysiw, 2001; Gan et al., 2006) and arrive at satisfactory identities post-injury (Nochi, 1998). As a result, many experience increasing social isolation, develop a range of mental illnesses, and fall short of the improvements in psychosocial functioning that may have been possible had they received the necessary support (Lezak et al., 2004; Thomas, 2004). In addition, recent research suggests that adjustment following ABI is a continuous and cyclical process, not a static arrival at a state of rehabilitation as once thought (Muenchberger et al., 2008).

Considering the aforementioned potential changes, it is no surprise that for individuals who can remember their pre-injury selves and have the capacity for self-awareness, experiences of identity confusion are extremely common occurrences (Myles, 2004). However, identity as it pertains to brain injury has not historically received a great deal of attention. Rather, biologically based concepts such as *personality* and *personality change* have been the focus of much scientific attention regarding ABI (Yeates et al., 2008).

As noted by Yeates et al. (2008), biological explanations of personality change following ABI have traditionally been derived from individualized notions of personality (e.g., Eysenck, 1967), where alterations to neurological structures are directly linked to changes in personhood. From this perspective, personality traits are unique to the individual, stable, biologically-based, and located in the brain. Thus, when an injury

occurs to a person's brain, personality changes are associated primarily with damage to specific cortical areas. Although this conceptualization of a direct brain-mind connection has been commonplace, at least in mechanistic conceptions of the world, alternate and more relational conceptions of personhood and identity have contributed a convincing argument that perhaps subjective and intersubjective factors play more of a role than previously thought. By conceptualizing identity as a relational process and proposing a more complex and integrative understanding of these changes, survivors are offered a way out of the determinism of personality trait theorists that leads to a dead end in terms of rehabilitation (Yeates et al., 2008).

Why has identity typically been an overlooked component of rehabilitation following ABI?

Haslam et al. (2008) claim that rehabilitation plans following ABI are increasingly recognizing the need for services beyond acute medical care, and that family and community-based services are emerging as important sites for attention post-injury. This is important because identity struggles for most individuals only becomes an issue post-hospitalization, long after many of their physical wounds have healed and direct medical care is no longer readily available (Muenchberger et al., 2008).

Another reason why identity has been overlooked in the rehabilitation literature has to do with a belief that the subjective experience of ABI survivors is not a reliable or important source of information when evaluating progress (Gracey et al., 2008). Instead of considering the perspectives of survivors, outcome measurements such as scores on depression indices and income levels are thought to be indicative of rehabilitation

progress (Johnson, Goverover, & Dijkers, 2005). According to Crisp (1994, as cited in Nochi, 1998), most studies regarding ABI have approached the topic of subjective experience from a medical or neuropsychological point of view and an individual's perspective is rarely valued. Despite research focusing on the subjective experience of people with acquired brain injuries, the *self* is still largely "regarded as a dependant variable of a brain injury" (Nochi, 1998, p. 869).

Perhaps due to advancements in qualitative methodologies, or a more accurate appreciation of the importance of subjective experience in rehabilitation for ABI survivors, there has been a shift in focus away from primarily neuropsychological and medical perspectives. Brown, Gordon and Haddad (2000) point out that subjective quality of life for ABI survivors is emerging as a key variable in predicting rehabilitation outcomes. This has stirred increasing interest regarding identity changes for ABI survivors and its impact on their lives. Several studies have indicated the drastic impact of ABI on a person's sense of self (Muenchberger et al., 2008; Nochi, 1997, 1998). A holistic rehabilitation program, established in 1978 by Yehuda Ben-Yishay in New York, was the first of its kind to seriously consider the psychosocial aspects of rehabilitation and focus specifically on addressing the reconstructive processes involved with identity (Ben-Yishay, 2008). Largely ignored for many years, Ben-Yishay's holistic rehabilitation program is now recognized as a superior example of an efficacious and comprehensive clinical intervention and is being replicated all over the world (Coetzer, 2008; Sarajuuri & Koskinen, 2006). Moreover, identity reconstruction is increasingly being acknowledged as a critical component of adjustment following injury, alongside (a) understanding of injury and limitations, (b) acceptance of injury (grief and loss), and (c)

adapting pre-injury skills and acquiring new skills (Levack, Kayes, & Fadyl, 2010).

Why is identity an important component of rehabilitation?

As Moldover, Goldberg, and Prout (2004) point out, “[ABI] is not only a neuropathological event but also a unique psychological process with profound implications for identity development” (p. 151). They go on to describe ABI as resulting in a severing of the continuity of who the person is, which has a profound impact on one’s sense of self. The authors view ABI as a developmental process that requires a grieving period in which the old identity can be mourned and the construction of a new identity can occur. Cantor et al. (2005) claim that after ABI, “the injured person lives with two images of the self: ‘who I am now’ and ‘who I was before injury’” (p. 531). These differing conceptions of self can be highly distressing, leading to the diagnosis of affective disorders such as anxiety and depression and severely restricting the possibility of successful rehabilitation post-injury (Cantor et al., 2005).

In 2005, Vickery, Gontkovsky, and Caroselli investigated the intra-personal variable of self-concept, or positive self-identity, for ABI survivors and its association with subjective experiences of quality of life. Their study confirmed previous research suggesting that development of positive self-identity was predictive of higher levels of quality of life post-injury. Cloute, Mitchell, and Yates (2008) expanded on this idea by explaining that despite achievements in significant rehabilitation goals (for example work, financial security, or mobility), individuals who experience a sustained disruption to their identity are more likely to experience mental health concerns, lack a positive sense of the future, and are less likely to report a good quality of life.

It has also been shown that identity disruptions are associated with increased difficulties in forming and maintaining social networks (Hoofinen, Gilboa, & Vakil, 2003; Engberg & Teasdale, 2004). According to Haslam et al. (2008), maintenance of one's social identity is predictive of well-being following ABI. In his latest study, Nochi (2000) investigated the self-narratives of ABI survivors and found that "people with ABI are not coping with their changed lives just by 'accepting' their injuries. Instead, they seem to ultimately revise their self-narratives" (p. 1799). Muenchberger et al. (2008) suggest that for survivors of ABI to experience a sense of control and fulfillment in their lives, they need to make sense of the profound changes associated with their injuries and come to some understanding regarding their processes of identity transition following injury. This is consistent with other literature that found ABI survivors ability to cope with changes in identity were predictive of anxiety levels (Dewar & Gracey, 2007). Considering these points, it is clear that understanding and adequately addressing identity disruptions is a crucial component of the rehabilitation process following ABI.

What research considers identity and ABI from a narrative and social perspective?

There is a growing body of literature examining narrative and social perspectives regarding identity construction following ABI. The language involved in descriptions of pre- and post-injury, social meanings, and discourses are emerging as important contextual parameters in survivors' post injury sense-making and identity formation (Yeates et al., 2008). Terms such as narratives and identity tend to be frequently used in these accounts of changes to personhood post-injury, signifying the recognition of a multiplicity of factors involved in (re)constituting the self.

A number of studies have taken an interest in the narratives of survivors. Within psychology, the turn to narrative was articulated in Polkinghorne's (1988) seminal work *Narrative Knowing and the Human Sciences*. This book had a profound influence on bringing forth the importance of narratives for organizing and understanding human experience. Polkinghorne makes a strong case for the centrality of meaning-making processes in human experience and the role that narratives play in organizing these experiences into temporally meaningful episodes. A narrative perspective purports a systemic view of human experience and an understanding of multiple realities versus one concrete truth. Summarizing the importance of narratives, Polkinghorne (1988) argues:

Narratives are a scheme by means of which human beings give meaning to their experience of temporality and personal actions. They provide a framework for understanding the past events of one's life and for planning future actions. They are the primary scheme by which human existence is rendered meaningful. Thus, the study of human beings by the human sciences needs to focus on the realm of meaning in general, and on narrative meaning in particular. (p. 11)

At first glance, narrative inquiries can appear to be solely a subjective and individualized process. However, the language available to tell the stories of our lives is highly reliant on the culture and power relations in which we are embedded. Michel Foucault's large body of work (e.g., 1969; 1977) has been instrumental in our understanding of how power relations influence the creation, maintenance, and authority of different regimes of knowledge or discourses. A more detailed review of his work is outside the scope of this thesis, yet it is crucial in our understanding of how self-narratives are implicated within psychosocial processes. In addition, the work of narrative

therapists such as Michael White and David Epston (1990) have extended Foucault's work by deciphering the numerous ways in which intersubjective processes are involved in the authoring of people's identities. In turn, they have created therapeutic interventions, such as the externalization of problems, attendance to alternate stories, and the establishment of communities of concern to assist people in resisting dominant discourses and facilitate the re-authoring of preferred stories.

In a series of studies, Nochi (1997, 1998, 2000) examined the self-narratives of survivors following ABI. In so doing, he demonstrated the reliance of the ABI survivor on the broader social contextual dimension. In his 1997 work, he identified a "void" in many survivors' self-narratives, largely due to memory problems interfering with their recollection of their accidents and portions of their recovery. Recognizing that many survivors carry with them something unknown, Nochi (1997) remarks that "[ABI] is a real crisis of the self" (p. 18) as the void in past memories serves as a barrier to self-understanding. Furthermore, Cloute et al. (2008) found that survivors' attempts to retell and fill in their lost memories are often challenged by the interpretations of close relatives and friends, highlighting the interpersonal components of re-authoring processes.

In his 1998 study, Nochi identified three areas of loss of self following ABI: (a) loss of self in relation to pre- and post-injury comparison, (b) loss of self in the eyes of others, and (c) discontinuity of identity through lost or disrupted memories. The first and third theme can be interpreted through an individualized lens, yet the second theme highlights the importance of relational processes regarding identity change. This finding was supported by the work of Weddell and Legget (2006, as cited in Yeates et al., 2008) as they discovered that while social neuropsychological factors did predict relatives' and

friends' judgments of identity change, it was the level of psychological distress in both survivors and relatives that was most predictive.

In his latest work, Nochi (2000) focuses on narratives from survivors who managed to reconstruct a coherent self-narrative and who felt "at ease" with their situation. He concludes that successful developments of self-narratives need to occur, "in interaction with other people, society, and culture" (p. 1802), as opposed to isolated rehabilitation programs. This may involve reorganizing interpersonal relationships and environments so that they support newly developing and preferred self-narratives.

The impact of social relations on identity was taken up by Haslam et al. (2008) in their investigation of stroke survivors, which also provides the first quantitative support for the importance of social processes in recovery. Drawing on social identity theory, which emphasizes "the importance of both social identities in general and social continuity in particular for well-being" (p. 672), these authors found that maintenance of group membership predicted well-being after a stroke. These findings highlight the role of social continuity in facilitating positive rehabilitation outcomes, and recognize the importance of group membership and social identity in neuropsychological rehabilitation.

The work of social constructionists such as Ken Gergen (1991) have been instrumental in our understanding of how social relations influence the construction of reality. Social constructionism "emphasizes subjectivity, language, social processes and the importance of understanding individuals as actively constructing meaning in the context of interactions with others" (Gracey & Ownsworth, 2008, p. 522). From a social constructionist perspective, there is no isolated, separate, individual identity, but instead a

co-constructed intersubjective relational process that is dependent on the social practices (e.g., creation of language, knowledge, processes of interpretation) that bring them into being (Gergen, 1985). From this perspective, “the mind becomes a form of social myth”, as it is “removed from the head and placed within the sphere of social discourse” (Gergen, 1985, p. 271). This does not mean that people cannot relate to themselves, or have a stable sense of self. However, it does recognize that accounts of a self are interwoven and dependent on the culture and social relations in which they are embedded.

Relational conceptualizations of identity have been emerging in recent neuropsychology and rehabilitation literature. In a recent study, Cloute et al. (2008) employed a social constructionist methodology to investigate the question of construction of identity following ABI. They were interested in how the language and interactions from dominant medical services influenced the creation of a “self” following ABI. Their discursive approach reveals that particular attention needs to be paid to how people are positioned and identified, particularly by the medical community. For example, binaries such as patient-expert, abnormal-normal, and sick-healthy often implicitly function in medical discourse and have a tremendous impact on how a person understands him or herself. Cloute et al. (2008) found that “medical model referencing left participants seemingly dependent upon the active interpretations of expert professionals and specialist services” (p. 665), leaving little room for survivors and their families to construct themselves in alternate ways. This example highlights the dynamic and social aspects of identity construction and supports other research that has investigated the passive

positioning of people with disability and illness when seeking medical support (Oliver, 1990).

Despite the presence of subjective and intersubjective methodologies such as phenomenology, hermeneutics, narrative inquiry, and discourse analysis, social science research is still largely dominated by objective and positivist research. Moreover, these objective metatheories have been shown to form the scientific basis for many of the so-called subjective approaches such as neuroscience and variations of phenomenology (Gergen, 1985). Wilber (2001) claims that we are currently living in a “flatland” (p. 32), a world that is lacking the *topography* of epistemological diversity.

The research presented above suggests that a growing interest surrounding the lived experience of survivors and particularly their narrative identities is gaining momentum as a valuable area for inquiry. Such knowledge is crucial for a deep and integrative understanding of the lived experiences of survivors and their families.

What is Adventure Therapy and has this approach been utilized with ABI survivors?

Defining AT.

Numerous competing definitions for Adventure Therapy (AT) exist, due to the diversity of activities, locations, and durations being utilized, as well as the multiple client populations and professions involved in AT experiences (Gass, 1993). One popular definition is that of Gillis and Ringer (1999): “[Adventure Therapy] is the deliberate, strategic combination of adventure activities and therapeutic change processes with the goal of making lasting changes in the lives of participants” (p. 29).

As Beringer (2004) points out, this definition attempts to include iterations of AT implying inclusivity of wilderness therapy, yet fails to mention the important contexts in which AT takes place. Clearly, this definition contains a significant oversight, and calls for definitions of AT that include contact with wild nature as a crucial component of the change process are present in the literature (Beringer, 2004; Greenway, 1995; Taylor, Segal, & Harper, 2010).

Presenting a detailed examination of the various definitions and theories of AT is beyond the scope of this research. For the purposes of this thesis, however, AT can be thought to include indoor, outdoor, and wilderness environments and can broadly be defined as “a therapeutic approach utilizing challenge and experiential learning in conjunction with therapist determined techniques” (Taylor et al., 2010, p. 77).

A growing body of research and subsequent meta-analyses have explored AT’s potential as a decisive treatment option for adolescents facing a diversity of challenges (Cason & Gillis, 1993; Davis-Berman & Berman, 1994; Hattie, Marsh, Neill, & Richards, 1997), adults with psychiatric diagnoses (Pawlowski, Holme, & Hafner, 1993), families (Bandoroff & Scherer, 1994; Gillis & Gass, 1993; Harper & Russell, 2008), and ABI survivors (Thomas, 2004).

Common outcomes attributed to AT include subjective experiences of empowerment; a reduction in problem-related behaviour; and the development of self-concept, self-efficacy, and an internal locus of control (Cason & Gillis, 1993; Russell, 2003). In addition, increases in self-awareness and interpersonal functioning are well-documented results of involvement in AT programs including significant contact with

wilderness environments (Russell, 2003). Finally, environmental education and a deeper connection to the natural world are outcomes that many AT programs strive to achieve (Greenway, 1995; Neill, 2003).

Adventure Therapy and Acquired Brain Injury.

Despite many overlapping challenges encountered by ABI survivors with existing AT populations, few programs incorporating AT principles exist for ABI populations. A review of the literature located only five studies examining AT and ABI, and of the studies conducted, all were oriented towards a program evaluation methodology, all included outdoor or wilderness environments, and three focused primarily on adult survivors.

Lemmon, LaTourrette and Hauver (1996) conducted the first study investigating ABI rehabilitation in an AT context. They examined psychosocial outcomes following an Outward Bound wilderness expedition program for professional women with mild ABI. Results suggested that due to an increase in awareness of their strengths and limitations, participants were better able to navigate challenges which subsequently led to higher levels of self-esteem.

A more recent study by Lorent, Peeters and Debaenst (2004) investigated the effectiveness of an outdoor challenge course program in addressing *anosognosia* or lack of awareness in adult ABI survivors. Despite a small sample size and non-significant results, the authors reported viewing substantial changes regarding participant motor skills, client-therapist levels of trust, and increases in participant levels of self-awareness. These results, although anecdotal, support the findings of Lemmon et al. (1996), but with a mixed gender population and instances of severe ABI.

Two of the studies directed attention to AT as an adjunctive therapy for an

existing ABI rehabilitation program in Australia. One was conducted by Thomas (2004) and examined outcomes from a unique wilderness adventure program serving adult ABI survivors from a community-based model. In particular, attention was focused on adjustment to injury and quality of life outcomes. Results indicated significant and long-term improvement of participants' subjective quality of life reports, including psychosocial adjustment. Specifically, outcomes included an increase in self-awareness regarding strengths and limitations; enhanced ability to manage emotions; shifts towards an internal locus of control; increased acceptance of uncontrollable issues; development of goal-setting and problem-solving skills; and recognition of the value of perseverance and strong social networks (Thomas, 2004). Participants attending post-program components reported greater levels of improvement and maintenance, signifying the post-program phase as a critical component of the AT intervention. In summary, this study supported outdoor-based adventure therapy programs as important adjuncts to community-based rehabilitation programs in improving the overall quality of life of survivors.

The other study investigating the same program discussed by Thomas (2004) was conducted by Walker, Onus, Doyle, Clare, & McCarthy (2005), in which a study of goal achievement was undertaken. Results indicated over 80% of participants were successful in achieving their identified goals. However, the study reported no change on self-ratings of depression, anxiety, stress, and general well-being, or on family ratings of overall difficulties. Of particular importance were the subjective responses regarding how the wilderness program and supportive group motivated goal accomplishment. Following successful completion of the wilderness expedition components of the program,

participants reported increased encouragement to focus on broader goals due to enhanced self-esteem. Further, the sequential presentation of goals and the creation of group cohesion supported this process.

The final study conducted by Shanahan, McAllister, and Curtin (2009) investigated AT models as a complementary intervention to cognitive rehabilitation with youth ABI populations. They examined the principles of AT and demonstrated congruence between its experiential orientation directed towards improving a person's ability to participate in daily environments and the processes and aims of cognitive rehabilitation. Moreover, the use of real-life contexts, as well as providing scaffolded learning opportunities, were pointed out as key components in both AT and cognitive rehabilitation approaches. They recommended that AT be further investigated as an adjunctive rehabilitation strategy for youth living with an ABI.

In summary, although the use of AT with ABI populations has garnered relatively little attention, the existing research strongly supports AT as a useful adjunctive and possible primary rehabilitation intervention following both mild and severe ABI. Importantly, all of the studies include models of AT incorporating some degree of contact with wilderness settings into their program designs. Thus, the wilderness context was a core component of all the interventions. In addition, although the addressing of psychosocial factors was implicit in all the studies, only Thomas (2004) devoted specific attention to psychosocial aspects of ABI recovery in general, and identity reconstruction in particular. Clearly, additional research is necessary to build on what has been undertaken. However, alternate methodological approaches investigating participant experiences and identity formation processes following involvement in AT programs that

include contact with nature would add considerable scope. This study consequently aims to contribute to the field of ABI and AT research by examining identity reconstruction processes following survivors' involvement in a multi-family outdoor adventure program.

Guiding Research Question

Having had the opportunity to be a practitioner in a multi-family outdoor adventure program (MFP), I experienced first-hand the profound changes that occurred pertaining to the participants' access to and reclamation of preferred identities. The positive responses from the five participating families and the staff and volunteers were nothing short of exceptional, so much so that four years later the program is still running, with many of the same original families, staff, and volunteers participating.

However, as mentioned above, the purpose of this thesis is not to evaluate or understand the mechanisms of change functioning in the program. Rather, this research is interested in contributing to intersubjective understandings of ABI by examining the following guiding question: *How do survivors of an acquired brain injury (including family members) story their lived experiences following involvement in a multi-family therapeutic adventure program?* Hence, this research warrants an inductive, exploratory qualitative research design within the spirit of social constructionism and narrative theory. It hopes to examine the shifts in narrative identity that occur for a select group of survivors of ABI, and illuminate how their involvement in the MFP contributed to their post-injury narrative identities. By selecting participants from this particular context, this research aims to contribute to the emerging dialogue surrounding relational conceptions of identity, acquired brain injury, and adventure therapy.

CHAPTER 3: METHODOLOGY

This chapter touches on two important aspects of methodology. First, it is concerned with ensuring transparency regarding the many procedural details of this research. An articulation of the many choice points encountered, alongside a rationale grounded within a rich and diverse body of literature is presented. Second, an attempt to illuminate congruence between the chosen methodology and “new paradigm research” (Lincoln, 2010, p. 3) is pursued. Also known as reformist research, these methodological approaches strive to move beyond conventional positivist ideas of knowledge generation (Lincoln, 2010; Polkinghorne, 2007) by developing methods that aim “to understand, illuminate, evoke, describe, narrate, and/or co-create knowledge of human experience” (Hoskins, 2001, p. 662). They are “chiefly concerned with rendering accounts of human meaning systems” (Gergen, 1985, p. 270). See Appendix C for a more detailed description of the epistemological differences between reformist and conventional approaches.

In pursuit of these intentions, this chapter is divided into two parts. Part One describes the specific qualitative approach utilized in this research, namely narrative constructionist inquiry (Sparkes & Smith, 2008), as well as the rationale for its selection in the investigation of shifting identities following acquired brain injury (ABI). Part Two presents the specific methods utilized.

Part One: Selecting a Congruent Methodology

Narrative constructionist inquiry.

Narrative constructionist inquiry (Sparkes & Smith, 2008) represents a plurality of methodologies that is congruent with the aims of this research. The underlying premise within these modes of inquiry is based on the insights from the *narrative turn* in the social sciences. Sparkes and Smith (2008) describe narrative constructionist inquiry “as a rubric for research efforts with diverse and shared theoretical musings, methods and empirical groundings, all revolving around an interest in narrative” (p. 296). Mahoney (2003) asserts that one of the most significant developments of the narrative turn “has been the realization that human beings are embodied stories and creative story tellers” (p. 100), and that “the stories that we tell ourselves about ourselves become the fabric of our existence and the literal meaning(s) of our lives” (p. 101). From this perspective, to gain an understanding regarding a person’s lived experience, attendance to their stories is essential. Clandinin and Connelly (2006) describe the ways in which such narrative knowing has influenced the development of the narrative inquiry methodology:

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. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the

phenomenon. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study. (p. 477)

Narrative inquiry as a mode of thinking and research methodology was largely influenced by the work of Jerome Bruner (1991) and Donald Polkinghorne (1988), as they were pivotal in bringing the insights from literary studies regarding narrative structures into the realm of the social and psychological. Both presented compelling arguments for the importance of narratives in organizing and understanding human experience. According to Bruner (1991), “we organize our experience and our memory of human happenings mainly in the form of narrative-stories, excuses, myths, reasons for doing and not doing, and so on” (p. 4). Echoing the work of Paul Ricoeur (1984), Bruner (1991) claims “we seem to have no other way of describing ‘lived time’ [except] in the form of a narrative” (p. 692). From this perspective, narratives are seen as a form not merely of representing, but also of constituting reality (Bruner, 1991).

In addition, Bruner (2004) strongly asserts that self-narratives are fundamentally shaped by both the culture and the acts of speaking, reflecting, interpreting, and reinterpreting our stories:

Eventually the culturally shaped cognitive and linguistic processes that guide the self-telling of life narratives achieve the power to structure perceptual experience, to organize memory, to segment and purpose-build the very “events” of a life. In the end, we *become* autobiographical narratives by which we “tell about” our lives. And given the cultural shaping to which I referred, we also become variants of the culture’s canonical forms. (p. 693)

Sparkes and Smith (2008) have drawn attention to the epistemological differences that exist within the plurality of narrative inquiry approaches. They describe two camps within which most narrative inquirers can be grouped. These are constructivist and constructionist positions. Although they share more similarities than differences, their main point of divergence has to do with whether emphasis is placed on subjective-cognitive (constructivist) or intersubjective-relational (constructionist) aspects involved in the “self-and identity-construction process” (p. 299). These are important distinctions, particularly for the narrative inquirer as they greatly influence what is attended to during the research process. Sparkes and Smith (2008) emphasize that attempts to definitively locate oneself need not occur. Rather, they suggest, “narratives might best be subjected to multiple forms of analysis and diverse writing strategies” (p. 303). Each perspective is valued for its uniqueness, while both share “an appreciation of people as active, socially constructed beings who live and lead storied lives” (p. 296).

Narrative inquiry as relational inquiry: The constructionist approach.

Although the methodology selected for this particular research is a narrative constructionist inquiry, clarification is needed regarding the constructionist orientation that is being adopted. Constructionist narrative inquiries have also been referred to as a form of *relational inquiry* (Clandinin, Murphy, Huber, & Orr, 2010; Clandinin & Connelly, 2000; Newbury & Hoskins, 2010a; Newbury & Hoskins, 2010b). A common assertion amongst these authors is that additional attention needs to be paid to the multiple intersubjective aspects of human experience when engaged in narrative inquiry. The research process is thought to be contained within a constant interaction among a “matrix of multiple relationships” (Gergen, 1998, as cited in Newbury & Hoskins, 2010a,

p. 229), all of which warrant attention in order to promote deep understanding. As Clandinin et al. (2010) put it, “narrative inquiry is the study of people in relation studying the experience of people in relation” (p. 82). Newbury and Hoskins (2010b) propose three important aspects that must be attended to for a relational inquiry: (a) the relationship between researcher and participant; (b) the relational dynamics within the lived experience of the participant; and (c) the participant’s subjectivity in relation to the significant events occurring in their lives. By paying attention to these three areas, they suggest that participants’ stories can be viewed contextually, promoting genuine understanding.

Speaking to the relational aspects of inquiry and specifically the researcher’s relationship to the participants, Clandinin et al. (2010) assert:

As narrative inquirers, our lived and told stories are always in relation to or with those of our participants. We do not stand outside the lives of participants but see ourselves as part of the phenomenon under study. As narrative inquirers, we study the lives of participants as we come alongside them and become part of their lives and they part of ours. Therefore, our lives and who we are and are becoming on their and our landscape is also under study. (p. 82)

Incorporating relational inquiry into the narrative inquiry process has particular implications for the researcher. First, it considers participants as active co-researchers rather than passive subjects. Second, researchers’ perspectives, interpretations and influence are intimately attended to and seen as unavoidable. Third, it considers multiple sources of information when generating a final text (e.g., conversations between and

among researchers, personal memos, participants' interpretations, participant interviews). Fourth, it pays particular attention to the points of relational intersection within the experience in question and how they constitute and are constituted by each other. And finally, it recognizes the ethical ramification of working relationally, which involves attending to the longevity and genuineness of the researcher-participant relationship, as well as the potential that the research process may have in providing counterstories to the dominant discourses being uncovered (Clandinin et al., 2010; Newbury & Hoskins, 2010b).

Having outlined the basic structure of the methodology employed – narrative constructionist inquiry from the constructionist perspective (Sparkes & Smith, 2008) – the next step is to describe the specific procedures involved in this particular inquiry. Much hesitation and trepidation were present at the thought of this task, as the prevalence and ease with which individualized discourses are smuggled into relational methodologies is all too common. Commenting on this tendency, Hoskins (2001) recommends:

[R]esearch decisions, such as which texts to use, which psychological and cultural theories to draw from and why, how, to position participants' voices in relation to the researcher's, and so on, are [to be] made through an ongoing process of reflexivity and a constant evaluation of the congruence (or lack of congruence) between content (inquiry), methodology, and practice. (p. 662)

Therefore, built into this methodology was my commitment as researcher to an ongoing process of reflexivity through personal journaling and a willingness to be constantly engaged in dialogue with colleagues to promote congruence.

Part Two: Detailing the Research Process

Participant selection.

At the time of data collection, five families were participating in the multi-family outdoor adventure program (MFP). Providing them the opportunity to be involved in the research was a priority, while simultaneously ensuring that non-participation would not compromise future services from Power To Be. While the perspectives of the children, the caregivers, and the people who had sustained the actual physical injuries were all important to capturing the full range of experiences, only caregivers and those who had acquired brain injuries were selected. Following recommendations from the qualitative narrative research literature regarding “purposive sampling strategies” (Polkinghorne, 2005, p. 139), participants were selected on the basis that they could, “provide substantial contributions to filling out the structure and character of the experience under investigation” (Polkinghorne, 2007, p. 139). For this reason, the children from the program were not selected, as doing so would require an additional six interviews with children ranging in age from 4 to 15 years old, warranting a significant amount of additional time and methodological considerations. This decision meant the omission of valuable perspectives. However, a narrative constructionist approach pays specific attention to the intersubjective relationships contributing to a participant’s relational matrix of existence (Gergen, 1999). This meant that the children would still be involved in this research, not directly, but ingrained in the narratives of their parents.

Thus, the target population fell into two groups. Group 1 consisted of people enrolled in the MFP who have acquired brain injuries. They were also required to have

sufficient levels of verbal fluency, language comprehension, and cognitive abilities to allow for freely informed consent to be provided. Details regarding how this was determined are provided below in the discussion of ethical considerations. Group 2 were the primary caregivers of the people in Group 1. In this instance, all of the primary caregivers were also their spouses, but this was not a requirement for involvement in the program.

Participant recruitment.

After receiving ethical approval from the University of Victoria Human Research Ethics Board (see Appendix D), Power To Be Adventure Therapy Society was approached for permission to conduct research that involved participants from one of their programs. Permission was granted along with a letter of consent outlining their support for this research (see Appendix E).

The adults from the five families who recently had completed the 2008 Power To Be MFP were invited to participate in the research, via a letter sent by Power To Be on behalf of the researcher (See Appendix F for a copy of this letter). The letter was composed by the researcher and reviewed and approved by the coordinator of the program. The letter instructed participants to contact the researcher if they were interested in participating. Four people with injuries responded and two of their caregivers. In addition, one caregiver responded without her family's involvement. A recruitment script was created (Appendix G) and followed during the phone calls. The details of the research were explained, including the purpose of the research, the time required, compensation, and issues pertaining to confidentiality and informed consent.

All of the potential participants who inquired decided to participate in the research. The final numbers were four participants from Group 1 and three from Group 2.

Research ethics.

Addressing issues regarding informed consent.

An informed consent form delineating the purpose, procedure, and risks of the research study was provided to each participant prior to their participation in the research (See Appendix B). This form described the anonymity, confidentiality, and ability to freely choose to participate or withdraw at any time during their participation. After reviewing the form with the participants and obtaining their consent, a signed copy was provided to each participant. In order to ensure ongoing consent, participants were given a copy of the original consent form at all subsequent meetings, which they were required to read again.

There was no reason to believe that the brain injuries incurred by the participants would impede their ability to provide fully informed consent. Moderate to severe brain injuries do not necessarily render survivors non-competent adults. All participants recruited were considered competent adults in their communities and were able to give consent in their own financial, medical, and legal dealings. However, recognizing the potential for diminished mental capacity to prevent the prospective participants from giving free and informed consent, individual subjective assessments of each participant took place to carefully determine whether any cognitive challenges might compromise their ability to fully provide informed consent. This was done by reviewing and discussing each component of the informed consent form with participants to ensure that they understood the material. No participants were deemed unable to comprehend what was expected of them, such as their right to withdraw or the limits to their confidentiality.

Addressing Issues Regarding Dual Roles.

Another area warranting attention was the issue of a dual role between the potential participants and myself (as both a previous practitioner and now a researcher). This was deemed not to be a concern: (a) The program had officially ended for that year as of September 2008, and (b) the pre-existing relationship with the participants was viewed as a strength of the research design, the rapport and trust that existed seen as a valuable asset in encouraging an atmosphere of openness and a willingness to share the details of their experience (Glaser, 1978; Newbury & Hoskins, 2010b; Polkinghorne, 2005, 2007).

The dual role was made clear by reminding participants at the beginning of each interview that they had the right to withdraw from the study. Also, it was clearly communicated that refusal to participate would in no way affect the receipt of any future services with Power To Be. This was explained to the potential participants at the time of recruitment and at the beginning of all of their interviews, as well as being laid out in the consent form (see Appendix B).

Addressing Issues Regarding Confidentiality.

Particular limits to confidentiality were identified due to the context of the research. Specifically, the participants were selected from a small group of families who participated in a very unique program. Therefore, due to the nature and size of the sample from which the participants were drawn, the possibility for individuals to be identified existed. To protect participants' identity as much as possible, pseudonyms were used to identify each participant. In addition, all participants were informed of the risk of personal identification due to the size and nature of the sample in the informed consent

process (see Appendix B). Moreover, all digital recordings of the interviews were stored on the researcher's password-protected computer and hard copies of the transcripts were secured in locked filing cabinets. Importantly, one of the participants (Todd) decided he would rather use his given name, as he wanted to ensure that readers knew that there was a "real" person behind his story. Thus, all participant names other than Todd have been changed to protect their privacy.

Participants.

It was an honour to work with these seven people (Todd and Kristine; Stan and Veronica; Robert; Mitch; and Diane). Four of the participants had experienced an ABI within the previous five years and of these four, all had received a formal diagnosis of an acquired brain injury (Todd, Robert, Stan, and Mitch).

Prior to their injuries, all four of them were working full-time, married, and had children. At the time of the research, Todd, Stan, and Mitch were on permanent disability and had not worked since their injury. Robert had recently begun to rebuild his business. All participants were thrilled at the opportunity to be involved in the research process.

Interview Process.

One-to-one interviews were selected as the appropriate means for collecting detailed accounts from participants. Interviews are readily used and recognized in narrative research as an effective means for exploring storied meanings (Kvale, 1996). In the fall of 2008, two, and in one case three, face-to-face semi-structured interviews were conducted over a two-week period. Although Seidman (1991) suggests that a sequence of three interviews with a participant is more likely to produce accounts of sufficient depth

and breadth, two interviews were deemed sufficient due to the previous relationship between the participants and the researcher. Interviews took place at a convenient location chosen by the participants and were conducted either at their homes in the greater Victoria area or at the Power To Be Victoria office.

The first interview focused on salient features, significant events and relationships of their families and lives just prior to their injuries, at the time of the injury, and the years leading up to joining the MFP. It was important to get a clear sense of the diversity of storied experiences leading up to their involvement in the MFP, while providing an opportunity for the “problem saturated story” (White & Epston, 1990, p. 16) to be articulated within a rich contextual understanding of their lives prior to entering the program.

Recognizing the limits of language to capture the depth of human experience, participants were encouraged to use figurative expressions to assist in unraveling the intricacies of their experiences. Participants were asked to bring pictures of themselves and their families prior to their injury as a way to prompt discussion of the significant events and relationships of their lives during that time. They were also invited to imagine their lives as an unfolding storybook and to begin by using this metaphor, along with the images, to describe the important chapters and events prior to the injury and the chapters and events immediately after. Using metaphor and imagery to assist in the expression, discussion, and understanding of the meaning-making processes for participants has been well documented in narrative inquires (Hoskins & Leseho, 1996; Polkinghorne, 2007; Newbury & Hoskins, 2010b).

Each interview was scheduled for approximately an hour and a half and all of them required at least that length of time. It was evident from the ease of conversation and the taking up of the storybook metaphor that this approach was congruent with how they understood their lives unfolding since the time of injury. In particular, there appeared to be an ease associated with conceptualizing their lives as having distinct periods: pre-injury, followed by the injury, and then life post-injury. Further, the use of the storybook metaphor allowed for the temporal dimensions of their unfolding lives to be easily attended to (Polkinghorne, 2007). Finally, probing questions were used alongside a stance of not knowing (Anderson & Goolishian, 1992), to promote participant reflection and encourage a thorough exploration of the “intricate multiplicity of experienced meaning” (Polkinghorne, 2007, p. 481) associated with their lives.

The co-creative process that unfolds during an interview between the researcher and participants is a recognized and valued component of a narrative inquiry (Clandinin & Connelly, 2000; Kvale, 1996; McLeod, 2001). However, guarding against simply producing the texts that the researcher expects is a vital aspect pertaining to the validity of the research. Addressing this concern, Polkinghorne (2007) recommends that interviewers maintain an “open listening stance and carefully attend to the unexpected and unusual participant responses” (p. 482). This was encouraged by adopting a curious and open stance, as well as by reviewing the transcripts prior to the second interview. The review served to identify particular points where the interview took a new direction and to question these moments with regard to the level of participant description versus researcher interpretation. Areas deemed in need of additional participant description were noted and addressed in the next interview. As well, participants were instructed to contact

me during the time between interviews if anything arose warranting additional discussion.

Following the first interview, participants were given the opportunity to reflect on the previous interview and comment on anything that stood out as warranting attention. In addition, major themes derived from the case notes were articulated and open to conversation, as an additional means for ensuring participant validation. Participants were reminded that the second interview was intended to explore their experiences during the course of their enrollment in the MFP and how they perceived the program contributed to changes in their lives. Continuing with the storybook metaphor, questions surrounding the salient features, relationships, and events from the program and how these influenced their unfolding life stories were explored. In addition, participants were again invited to bring photographs from their time in the program to assist in the telling of these chapters. Being personally familiar with the program was helpful with regard to prompting questions surrounding specific aspects of the program and significant events that occurred. In addition, having a solid background in counselling skills was viewed as an asset, as it promoted accepting relationships, active listening, and focus on the participants' experiential world (Polkinghorne, 2005). All interviews were recorded with a digital recorder and researcher memos were written following each meeting.

Interview Transcription.

A local professional company transcribed interviews to assist in a quick return making it possible to review the transcripts prior to the second interview. Using transcription software, vocalizations were recorded, including exclamations such as “ums” or “ahs”, pauses, and stutters. Transcriptions of the second interviews took place during the following two weeks.

Polkinghorne (2005) claims that narrative researchers are required to recognize that important “information and nuance is lost when oral data are transcribed into written text” (p. 139). In order to address this concern, all interviews were listened to immediately following their recording and detailed notes were taken regarding moments during the interview that might be lost in the transcription process. This process was intended to assist in the deepening of the reflexive memos written immediately following interviews.

In addition, the texts derived through narrative interviews are often referred to as data. However, it has been pointed out how this term is derived from quantitative investigations and does not fit with the language of experience that is the attention of qualitative inquiry (McLeod, 2001). Thus, the term *accounts* is used instead.

Analysis.

Upon completing interviews with the seven participants, it became evident that collapsing their stories into thematic highlights would greatly undermine the integrity and depth of their unique experiences. Moreover, including all seven complete stories would be too much information to capture in this thesis and perhaps water down the richness of

the analysis. Thus, for the purposes of this research, three exemplars were chosen from the group of participants and were the focus of the analysis. These exemplars were chosen based on the level of detail explored in their interviews, as well as their noted ability to articulate their experience in an insightful and accessible fashion.⁵ Each exemplar represents a different perspective, highlighting the multiplicity of experiences involved in being a survivor of acquired brain injury. Importantly, all participants were invited to review the analysis as it progressed and encouraged to take an active role in voicing any discomfort, suggestions, and expansions to the proposed interpretations. Thus, the text created was intentionally written as a tentative, living document that was co-created and negotiated between the researcher and participants (Clandinin et al., 2010). This was also accomplished by inviting participants to co-present preliminary research findings at two community events, “creating spaces for participants to continue to tell their stories in the margins of the interim research texts” (Clandinin et al., 2010, p. 84).

⁵ The researcher recognizes that some of the participants with ABI struggled to articulate their stories due to language and memory difficulties. This raises an important issue regarding how a narrative approach privileges those who are verbally proficient. Further attention is needed to investigate different qualitative methodologies that can include these additional perspectives.

CHAPTER 4: SHARING STORIES

“People are wounded not just in body, but also in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away.”

-Frank, 1995, p. xii

This chapter presents the valuable and diverse stories of Todd, Robert, and Diane. It explores the shifts in narrative identity that occurred following their brain injuries and how involvement in the MFP was perceived to facilitate movement towards preferred identities. The intent is to demonstrate the importance of narratives in the construction of identity post-injury and how social dimensions play a pivotal role in the availability and construction of preferred identities. It is hoped that such efforts can reveal valuable directions for future research and practice.

This chapter begins by revisiting narrative identity and examining how an analysis of personal stories can aid in illuminating the relational processes involved in the construction of identity. In turn, a narrative identity analytic is used in the presentation of the stories of Todd, Robert, and Diane. It is important to add that the process of writing itself was a key component of the analysis. Through writing, reflecting, revising, and responding, new ideas and interpretations were rendered possible (Richardson, 1994).

Revisiting narrative identity

As Holstein and Gubrium (2000) describe, a person’s narrative identity is a combination of the narratives available to tell the stories of their life, the specific biographical events that shape interpretations, and the social context in which identities are relationally negotiated. This particular comprehension of narrative identity is one among a continuum expressed in the literature, each placing a different degree of

emphasis on either the psychological or social processes involved in the creation of *personal* identity (Sparkes & Smith, 2008). However, amidst their differences, commonality exists:

[O]ne main loci of agreement among scholars influenced by the turn to narrative is that identities and selves are shaped by the larger socio-cultural matrix of our being-in-the-world and, at the least, narrative implies a relational world. (Sparkes & Smith, 2008, p. 8)

Thus, the analysis that follows is one interpretation of the many different paths available. Yet, at the same time, it recognizes the relational processes involved in the construction of identity and therefore employs a relational narrative identity analytic. Echoing the work of Somers (1994), it aims to reconceptualize “the subject-object dualism of modern social theory, [...] and transform the dichotomy into numerous matrices of patterned relationships, social practices, and institutions mediated not by abstractions but by linkages of political power, social practices, and public narratives” (p. 634).

Employing a relational narrative analytic requires bringing attention to personal stories and meaning-making processes (Mahoney, 2003) while at the same time recognizing the cultural storylines and relational processes that are involved in the construction of an individual narrative.

Somers (1994) provides a useful framework for understanding narrative identity along three interrelated dimensions. The first is *ontological* narratives, which are the stories that people tell themselves and others during momentary interactions and habituated ways of being. Somers (1994) makes the point that ontological narratives are

neither considered natural nor are they located within a person's mind; likewise, people can neither freely choose their narratives nor create them at will. Rather, they are "drawn from a limited repertoire of available narrative resources that are, above all, 'social and interpersonal'" (as cited in Smith & Sparkes, 2008, p. 18). These social and interpersonal narrative resources make up the second dimension referred to as *public* narratives.

According to Somers (1994), they are "those narratives attached to cultural and institutional formations larger than the single individual, to intersubjective networks of institutions, however local or grand" (p. 619). Finally, the third dimension is linked to the previous two and is termed *metanarrativity*. Somers (1994) describes these as "the 'master narratives' in which we are embedded as contemporary actors in history and as social scientists" (p. 619). Although usually beyond our awareness, these narratives are the dominant world views that come to define our time. Examples include capitalism, modernity, individualism, and liberalism.

These three dimensions are a useful heuristic in which to explore narrative identities. Representing different levels of inquiry, they are not discrete or separate from each other. However, to facilitate an "experience-near" (White, 2007, p. 40) description of the participants' stories, focus will be placed on the ontological and public dimensions in the presentation of the following stories.

Embarking on a journey: The stories of Todd, Robert, and Diane

Clearly articulated in the three stories, acquired brain injury (ABI) has been a critical turning point, a major biographical event and thus, a significant narrative disruption. Recognizing that the narrative identity approach situates the individual within dynamic relationships and stories, it is expected that shifts within the narrative identities

of the survivors interviewed will be accentuated due to their injuries and subsequent involvement in the MFP. Moreover, it is hoped that categorical or internally stable concepts, such as “brain injured person” and “caregiver” will be shown to be narrow and limiting representations of a multilayered, processual and relational narrative identity (Somers, 1994).

In addition, the researcher has chosen to edit the participant accounts presented below in an attempt to enhance their readability. However, this was done tentatively and sparingly in order to respect participant meanings and not replace their voice with that of the researcher. Specifically, the removal of verbal expressions (“ums”, “ahs”, and “likes”) and attention to basic sentence structure was attended to.

Todd’s Story: I was a doer, an athlete, a father, and I will be again!

Introduced earlier, Todd is the proud father of two young children with his spouse, Kristine. Having sustained a serious brain injury due to a collision on the soccer pitch in 2001, Todd’s life changed dramatically. Responding to a request to describe himself and his family prior to his accident, he shared the following characteristics:

Prior to my accident I was more of a doer. Very outgoing. I was athletic. Very active in the community. I used to coach volleyball at the university and high school. I used to referee volleyball, play soccer, and did a variety of sports. I loved to travel. And that’s something we liked to do as a family, as a couple. Anyways, we were excited about starting a family. We knew we wanted to be active as well . . .

Apparent in this short excerpt are clear ontological narratives that Todd is drawing upon to express his *previous self*. Importantly, all these personal narratives are shaped and given meaning through the public narratives in which they are embedded. For example,

Todd refers to himself prior to his injury as a doer and this was a narrative that he used to describe all areas of his life, whether it was vocational, recreational, or personal pursuits. For Todd, the specific meaning of being a “doer” is largely contingent on his social world. There is no universal consensus on what being a “doer” means. Rather, his particular understanding of being a “doer” is possible through the creation of its opposite – in this case his current experience of being inactive – and both constructs are negotiated within the specific interpersonal world in which Todd is embedded (Gergen, 1999). The same social processes are functioning in his articulation of himself as the “athlete” or his “active” involvement in his community. Todd also describes himself as being able to contribute in meaningful ways, and importantly, this was acknowledged by his friends, family, and work colleagues. Todd explained that just prior to his accident he was promoted to senior management at work. He also makes mention of his shared desire to start a family, indicating the expectation and excitement for future narratives such as parenthood.

In summary, accomplishment, ease, expertise, and active participation in his family and community are narrative threads present in his story of his previous self. A sense of expansiveness and contentment with regard to the seemingly boundless possibilities is also evident. However, the telling of his *present self* marks the emergence of a different story, one in which the expansiveness and ease of his previous self are contrasted with the restraint and frustration that he now experiences:

I want to talk about my physical and cognitive disabilities and just say that I’ve been diagnosed with hemiplegia on my right side and that my cognitive disabilities are poor speech, finding my words, planning, and organizing . . .

Fatigue is a big problem. Mentally, it takes a lot of energy to think of everything, so that's difficult. Even walking is difficult. It's not routine anymore. It's not subconscious . . .

Physically it's hard to chase the kids around so that can be challenging. In particular, when I need to gather the kids together, an able-bodied person would be able to round them up no problem, whereas I have difficulty. My movement is so slow I have difficulty doing that . . .

Thinking about all the things that I used to be able to do and how hard they are now is incredibly frustrating. The most frustrating times are when I try to do what I used to do so easily and find that it is almost impossible. It causes so much frustration which leads to anxiety, which leads to anger.

It is apparent that Todd's current experience of himself is not congruent with how he narrates himself prior to his accident and that this is a cause of great frustration. He expresses a sense of physical and cognitive limitation, which is contrasted with both the stories of his previous self as well as his conception of an able-bodied person. Present in his account is an assumption with regard to the existence of a universal "able-bodied person" to whom he compares himself. However, as demonstrated above, no such universal definition exists. Rather, the creation of a binary between able-bodied and disabled is a relational process situated within Todd's particular social world. This binary is hierarchical, with the latter being positioned as *lesser than* and the former being the desired and *normal* state (St Pierre, 2000). In addition, Todd's self-storying of being disabled is supported by medical narratives, such as his diagnosis of being hemipelagic, which is an institutional label that has considerable "*authority*" (Davies, 2000, p. 67) over how Todd narrates himself.

Another important aspect of Todd's description of himself prior to his accident is that it was not contested within his social world. Most notable was how he storied Kristine's viewing of him prior to his accident:

Dave: How would Kristine have described you, do you think, before your accident?

Todd: Intelligent, athletic, organized, and logical. Spock-like.

Dave: And would you say loving?

Todd: Yes, diplomatic, caring, supportive for sure. Yeah, we had a very tight relationship. Oh, she would describe me as her rock.

In this conversation Todd introduces two telling metaphors that he is drawing on to make sense of his life prior to his injury. Recognizing that metaphors are more than merely descriptive and linguistic tools residing inside a person, but rather are vehicles for cultural meanings (Lakoff & Johnson, 1987), they are helpful in illuminating the co-constructed nature of Todd's narrative identity. In particular, Todd refers to himself as "Spock-like" and that he was Kristine's "rock". The former is a reference to the fictional character from the television show *Star Trek*, who is known for his lack of emotion and unprecedented use of logic and rationality. The latter is speaking to his role as husband and provider. Although the connection was not made intentionally at the time, it is interesting to note how the narrative of emotion, and specifically love, was introduced into the conversation by my question following the referencing of a prominent character who is unable to experience emotion. This is indicative of the dialogical process occurring between Todd and myself in the conversation. The narrative regarding being "a loving spouse" was taken up by Todd and extended with the metaphor of their relationship being "tight" and him being her "rock". The metaphor of a rock points to particular narratives of masculinity, such as strength, security, and the stability he

provided for his wife prior to his accident. Importantly, Todd's narratives of being a rational, strong, loving, and providing spouse are expressed as being acknowledged by Kristine. Following his accident, this appears to no longer be the case for both Kristine and, in some cases, for Todd as well:

Kristine doesn't trust my judgment with a lot of things. And, I'll admit that I have judgment problems. That some of my so called "rational" decisions aren't quite as rational as I think they are.

For Todd, many of his previous narratives are still desired and present in the telling of his current self. In the above account, one of his defining qualities, rationality, is subject to question by both himself and his wife following his injury. This tension between his previous self and his current self appears to be the source of a great deal of conflict both personally and socially for Todd. Thus, a dominant theme is that the changes perceived as limitations are not welcome and that progress is imperative so that he can return to how he used to be. It appears that when attempts to enact previous ways of being are met with limited success, this threatens to shift Todd away from his previous, and in this case, desired identity, and towards one of a "disabled man". Such shifts contribute to great discomfort, not only for Todd but also for his family, especially when anger is the end result:

Todd: I find that I get tired way more easily and fatigue leads to frustration, which leads to anxiety because I am not confident that I will be able to do the task at hand, despite knowing that I used to be able to do such things, which then leads to anger. And my anger can have detrimental effects on those that I love the most. I get set off by things that, when I'm able to think back on them, they are trivial. But during the time, they seem to be the most significant events.

Dave: At the time they seem important enough to be mad about?

Todd: I was always very organized and my desk at work was spotless. And I'd pride myself on that so if you look around this house isn't necessarily the most spotless, the way that I would like it to be. I am trying to work through that and trying to do things on my own to clean the things up around here but at the same time I've got two kids that, well, that create messes as kids generally do. And Kristine is busy tending to their needs so she doesn't necessarily have time to clean up so that leaves me with it. If I want this, if I want it to be clean, I've got to take some of the tasks on to myself. But being fatigued is a problem. So I try to clean up, then get tired doing it. Then the tiredness leads to frustration, then I end up thinking why am I cleaning up after these guys, and then I get angry and then next time I see them I just flip out and say, why do you guys create these messes? And, and then I've hurt them.

This account demonstrates the importance that Todd places on particular storylines present prior to his injury (e.g., being an organized and clean person), and how his physical injuries create barriers preventing him from being able to live out those storylines in the same way he used to. This proves to be immensely frustrating for Todd, as he clearly still desires and values those storylines. Thus, during moments where Todd perceives himself as unable to enact his previous narratives, frustration results, which leads to experiences of anger and the eventual harming of his loved ones.

The work of Arthur Frank (1995) is useful in illuminating how Todd's particular narrative structure may be shaping his experiences of recovery and subsequently experiences of frustration and anger. Frank (1995) examined the narratives of survivors of what he calls body/self disruptions (spinal cord and cancer survivors) and concluded that three different narrative types appear to be useful in understanding how people come to story themselves following such disruptions. They are the *restitution*, *quest*, and *chaos narratives*. In Todd's case, the *restitution narrative* appears to be evident in the telling of his story. This particular narrative structure has the basic storyline: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank, 1995, p. 77). For

Todd, this translates to, prior to my accident I was able-bodied, today I am disabled, but tomorrow I'll find ways to be able-bodied again. The restitution narrative structure has an affinity towards the previous self (Frank, 1995), as Todd indeed appears to place importance on previous narratives and ways of being in the world. Further, it lends itself to a particular rendition of hope; one that focuses on finding ways to facilitate change towards how things used to be (Smith & Sparkes, 2004; Smith & Sparkes, 2005). Here are a few additional examples of this narrative structure in Todd's story:

Obviously things have changed. So, all my energy is now going towards what needs to change back in order to get things back to how they were . . .

Progress is very slow, but I am learning what I need to do so that I can continue to challenge myself and return things back to how they were . . .

I am a realist. I know I won't be able to return to exactly how I was. However, advances in neuroplasticity suggest that although the injury still exists, new "ways" can be found to do old things, both physically and neurologically.

According to Frank (1995), a crucial component of the restitution narrative is the belief that recovery is possible. Smith and Sparkes (2005) observe that this promotes a type of concrete hope that tends to be reliant on medical advancements and has rigidity with regard to other possible narratives that do not involve progress and returning to one's previous self. The following account details an interaction between Todd and a counsellor, in which a competing narrative of progress and recovery was introduced that threatened to strip Todd of his particular belief in progress and recovery, and is a telling example of the importance he places on both medical knowledge and hope:

Todd: I've always been encouraged by research that has talked about neuro-mapping and the plasticity of the brain. It gives me hope and hope is what keeps me going.

Dave: Can you tell me a bit about that?

Todd: I was once talking about neuro-remapping and neuroplasticity and I had a counsellor who said, oh it doesn't work that way, all the research shows that you won't get any better. Something to that effect. And that just devastated me. And I subsequently fired her as a result. And I thought, you're not going to take the hope out of me. And I thought, no matter what life throws you there always has to be hope so that you can keep yourself going no matter what your limitations are.

Dave: Mmhmm. So at that moment hope was one of your strongest allies, and this counsellor was threatening to take it away.

Todd: Yes. I'm still bitterly angry. It makes me so mad that somebody who's supposed to be an expert in that field just squashed, or attempted to squash my fundamental belief that is going to make me better.

Dave: So if you had the possibility to give some advice to this counsellor, and if she were to do it again, what do you think you would have needed from her?

Todd: For her to be sensitive to how important hope is to me. I don't know if I communicated that hope was really important to me, but as far as I'm concerned, I think any brain injury survivor, any person, any survivor period, needs hope, as it's crucial to their existence and survival.

Todd's perception of insensitivity on the part of the counsellor with regard to his understanding of hope and progress was a serious threat to his dignity. Todd was able to stand his ground and subsequently fire this person, despite her expert status as a professional in a position of power due to the client-therapist relationship. Clearly the importance of Todd's narrative structure was overlooked by this particular therapist, and had Todd not been able to voice his discontent, the situation could have contributed to yet another narrative disruption with unknown consequences. The point is not to lay blame on the actions of the therapist, or determine who is right or wrong with regard to whether Todd will actually regain his previous abilities. Rather, it is to draw attention to the

importance of Todd's narrative structure in shaping his experience of his situation and how different social interactions come to shape his experience of recovery.

Shifting identities: Alternate stories and the MFP.

The previous section attempted to focus on Todd's narrative identity both prior to and following his injury. Attention was placed on identifying the main narratives, as well as how they were negotiated through a matrix of relationships (public narratives and social interactions). Although Todd had numerous characteristics by which he described himself, an attempt to locate these within social or intersubjective processes occurred. Todd's story of being a doer, being active, being organized, being a father, and of his dissatisfaction with being a "disabled man" were all embedded and possible due to the specific social/interpersonal context of which he was a part and the meaning that was made available (Gergen, 1999). In addition, public narratives such as progress, medical advancements, and development were evident in his story and came to shape his interpretations of his recovery and his relationship with hope.

This next section aims to explore how Todd's involvement in the MFP led to additional shifts in his narrative identity. The intention is to create space for sharing the multiplicity of identity conclusions that exist within the nexus of relationships that constitute a person's life (Gergen, 1991) and how some of these alternate stories or "unique outcomes" (White, 2007, p. 61) were made available, created, discovered, tried on, and possibly challenged during his involvement in the MFP. It is hoped that these stories can support the ongoing process of presenting rich and complex renderings of the lives of survivors that demonstrate the numerous possible storylines beyond the singularity of a *brain injured person*.

Escaping, reclaiming, and spending time in the healing context of nature.

Todd was referred to the program by his social worker to facilitate outdoor recreational opportunities for both himself and his family, something they had done prior to his injury. Further, it was intended to provide opportunities for positive experiences in the context of a supportive community. What follows is Todd's initial response regarding his experience of the program:

The program is an escape. It lets you forget your frustrations and your fears. You're able to just concentrate on the important things. The volunteers and staff are able to take your challenges and set them aside and take care of them for you. And you can just concentrate on the important stuff: having fun, being with your family, being in the outdoors, taking in the adventure.

This excerpt signifies a shift in Todd's narrative of himself as he explains his involvement in the program. Specifically, he describes how he is able to "escape" and "forget" his frustrations and his fears, while focusing on the "important stuff". As outlined in the previous section, Todd is alluding to escaping from the tensions that exist between his previous and desired self and his current experience of himself. In addition, it is interesting to note that what is important for Todd in this instance (fun, being with family, being outdoors), differs from what was previously explained as important (tidy, organized, rational), emphasizing the importance of context and relationships in the emergence of narrative themes. When further inquires were made into this experience, Todd eagerly expands:

It gives us time to concentrate on us. If we were to try and go kayaking on our own or do any of the activities on our own we'd have to think about mobility issues, we'd have to think about fatigue issues, we'd have to think about food preparation or the planning around it. The logistics alone are a day's activity. They take a day just to prepare.

Todd is commenting on the realities involved in living with physical/cognitive challenges and how difficult they can make accessing the types of activities that both he and his family desire. Also, he expresses how removing the logistical challenges open up new possibilities that are in line with how he prefers to story himself:

Like I said before, I was quite an outdoorsy person. I was a coach. I was an athlete. I was a doer. I was looking so forward to that as a parent. I was looking forward to being the coach for my son. I was looking forward to going travelling with the kids. And now it's not only thinking about travelling, it's thinking about, where does my wheelchair go? How do I get around? We used to be able to get up and go. Okay, we're going to do this. Spontaneity was a big part of our lives . . .

I've always envisioned myself as a doer or a physical father. I like to lead by example. I wanted to demonstrate those abilities to my kids. So they can develop those similar skills. The program provides me with opportunities in which I can get up and try and do those similar things. For instance, we played soccer one time and just getting up knowing that someone was behind me in case I fall or knows my level of fatigue, gave me the confidence to do it.

The program takes care of the details and enables us to do these things. I get supported in playing soccer with my kids. Coaching them, kayaking with them. So many activities that I would have done, that I want to do, and I can because of the program.

These are extremely important points. Todd is communicating his profound loss regarding the things that he can no longer do, and the role the program plays in providing alternate narrative possibilities. Todd's preferred stories are once more available with the support of the program. He is able to experience a sense of congruence between his previous self as of a coach, an outdoorsman, a family man, and how he is currently living his life. Further, this appears to support his relationship with hope and progress, as these experiences of reclaiming his past identities provide reassurance that his desired goals for recovery are possible. However, Todd also notes that in some cases it is not about

reclaiming previous identities, but knowing that important aspects of his previous identity are being attended to:

Again, the planning and the organizing is really fundamental and is something I would have done in the past. I was always the person who was organized on our trips. I would plan where we're going, what we're doing, and what time we were doing it. That was my role. So the program hasn't necessarily given me that role back. But it facilitates things happening in areas that I'm still concerned about, and to know that those areas are covered by somebody is really important to me. It is very anxiety-reducing.

Todd is describing his previous role as the family organizer. This narrative is likely bound up in the story of himself as his family's "rock" prior to his injury. He was the one who organized trips, took care of the details, and ensured things ran smoothly. Clearly, Todd is still interacting with this narrative and appreciates knowing that his family's needs are taken care of during involvement with the program. Recognizing the numerous ways in which Todd has not been able live out this narrative, it comes as no surprise that he describes relief and an absence of anxiety when this role is attended to. In addition, Todd explains the importance of nature as a therapeutic and restorative context:

Dave: Do you feel that the nature component was important? If this was totally an indoor program do you think that would have made a difference?

Todd: I studied biology in university, and geography, and had a strong relationship with the outdoors prior to my injury. I always realized the value of the fresh air, the sun on your face, the water, the rain. Knowing that nature was such a big part of our lives prior to my injury and that both myself and my family can be outside in nature is very important to me. There is something within nature that is therapeutic in itself. It's not an institution. It's not a hospital. It's not a rehab gym. It's not a therapy session. It's not therapy in the traditional sense. It provides therapy that's fun. That's intrinsic. You don't have to think about it.

In this account, Todd is drawing on previous narratives about himself, his family, and nature. In particular, he presents a familiar story of nature as a place of peace, restoration,

and a valued context for healing (Gergen, 2008). Further, he articulates a specific narrative shift that occurs when he is spending time in nature. Contrasted with traditional therapy (hospitals, rehab, office-based therapy), he explains that being in nature is inherently fun. Thus, for Todd, being in nature facilitates a sense of distancing himself from the *work* that is involved in progressing towards recovery and he draws on what he perceives as nature's intrinsic healing properties rather than relying on medical procedures and the narratives associated with it. Hoping to further explore this narrative shift, the following conversation unfolded:

Dave: So what would some of the benefits be of this type of therapy?

Todd: Freedom. Forgetting about your challenges. I can't put it into words. It's...

Dave: You are no longer identified as your disability.

Todd: Yes. You forget your challenges and you're able to be normal. If you can use that word. Because nobody likes to be different.

Dave: Yeah, so you feel one. You feel connected.

Todd: Yeah. You don't feel separate or different. In the forest, there it's peaceful. And the peacefulness leads to calm, relaxation, and a lack of anxiety.

Here Todd explains the profound shift that he experiences while in nature. The relational process of this interaction is demonstrated in the back and forth motion, where ideas are taken up and expanded as the conversation unfolds. In particular, Todd introduces the concept of freedom and again brings up forgetting about his challenges. This is interpreted as an experience of shifting away from his identity as disabled and Todd further expands that it allows him to feel "normal" and "not different". His experiences in nature appear to provide freedom from the identity conclusions that exist when he interacts with narratives from the medical community (e.g., diagnoses and progress) or faces the challenges entailed with his injury. The narrative possibilities available while

interacting with nature seem to facilitate movement away from identity conclusions that threaten to position Todd as a *disabled man*, or no longer the person he used to be. As a result, it facilitates an apparent sense of wholeness and connection that leads to calm, peacefulness, relaxation, and ultimately an absence of anxiety.

Further, the supportive community established through the program has an important influence on the narratives that are available for Todd. As with his experiences in nature, Todd describes a sense of being accepted and not positioned as different:

I've always felt accepted by the group. Again it's an area where I can forget about my challenges and disabilities. It's not pointed out to me in every case that I have a disability so I can forget it.

He also discusses the importance of viewing other people in similar situations face and overcome challenges:

Seeing people with similar disabilities make achievements is inspiring. Also, seeing families who are getting along. It's inspiring for everybody I would think, not only the people who have the disability but for everyone involved.

Being in a supportive social context where the narratives available surrounding brain injury do not focus on disability and challenges facilitates Todd's ability to "forget" about these undesired narratives and opens up possibilities for alternate stories. Further, being able to perceive other people overcoming challenges and interacting positively with their families appears to support the maintenance of hope in his life. As previously discussed, hope for Todd is tied into narratives of progress. Therefore, seeing examples of other people who are progressing serves as a powerful reminder of his own capacity to do so. Both of these statements point to the importance of the social world in co-creating Todd's narrative identity.

Postscript.

Upon completing a version of this story, Todd was given an opportunity to provide his feedback. Overall, Todd was pleased with what was written, although he expressed concern regarding the potential for him to be misrepresented and portrayed as a “man in denial”. The following comment was written at the end of his edits:

I am concerned that this story seems to portray me as someone who doesn't accept my “disability” or the fact that I don't accept the symptoms of my disabilities and that I even deny it. I fully accept it. I'm just a taskmaster that wants to do more and more, at my “old” pace/abilities. I realize I won't recover 100% like a broken bone does, but I will continue to make progress no matter how small!!! That is the “hope” that I cherish!

These significant comments are a valuable reminder of the impact and prevalence surrounding narratives of denial that many survivors come up against. In Todd's case, he expresses his discomfort regarding the possibility of being portrayed as a brain injured person who does not have a realistic grasp of his situation. Evidently, Todd is aware of his disability and deeply concerned with not being portrayed as a person in denial. This brings up the issue of “lack of awareness” following ABI and further points to the importance of considering survivor identity and dignity when encountering such issues. Additional conversations with Todd revealed that his concern resided in the use of terminology, such as his previous self and restitution narrative, as they were interpreted as not acknowledging his awareness of the extent of his injury. A conversation expanding on these terms and locating them within a specific body of knowledge clarified his concerns.

Another valuable aspect of Todd's account is that it crystallizes many of the points made above regarding his narrative identity. In particular, it highlights how his "old pace/abilities" guide his present experience of recovery and how his narrative of hope is intimately tied with his narrative of progress.

Summary of Todd's story.

The challenge of presenting Todd's story, highlighting the narrative structures, and describing some of the shifts in identity that occurred during his involvement in the MFP cannot be overstated. Of great concern is doing justice to its depth and richness, while not overloading the reader to the extent that opportunities for understanding become lost or diminished. For Todd, experiences in the program were perceived as welcomed alternatives to the daily struggles encountered at home. Importantly, additional and preferred narrative possibilities were made available that were congruent with his dominant storylines. Finally, experiences with nature and with the supportive community appeared to shift Todd into novel narrative territory, which contributed to an experience of great relief.

Needless to say, the interpretive process never ends and there are numerous additional areas of inquiry left to explore, for example, details regarding the ways in which Todd's narrative identity as a spouse, father, and community member evolved throughout his involvement in the program. How were these shifts maintained or threatened while not involved in the program? These are important lines of inquiry to follow at a later date. The intention was not to arrive at neat and tidy conclusions, but rather to illuminate and highlight the multiplicity of Todd's experiences and demonstrate how different contexts and their associated narrative possibilities facilitated the

presentation of alternate and, in this case, preferred identities. The other participant accounts will serve to demonstrate the diversity of experiences that occurred following involvement in the program.

Robert's Story: I am the Authentic Robert, I have been, I am, and I always will be!

Robert's accident occurred in the summer of 2003. He recounts how he had booked off time from his business, arranged with his wife to care for their child, and was scheduled to ride his motorcycle for the day, arriving home in time for supper. Miscalculating a curve in the road, Robert did not make it back that day to share a meal with his family. Rather, he was thrown over 60 feet off the side of a mountain and would spend 15 weeks in the hospital, two and a half of those in a coma.

Robert's story of his accident is retold in meticulous detail, exactly how many fractured bones (17), who his emergency technicians and doctors were, as well as his experiences and insights from the coma state. According to Robert, he only has snippets of memory pertaining to the accident and the weeks following. To assist in rebuilding a complete picture of this *puzzle* of an experience, he has relied on his medical and police records and indirect memories supplied to him by other people. Common among brain injury survivors, Robert experiences a void in his story of himself immediately following his accident and is deeply concerned with piecing it back together (Nochi, 1998). However, his memories of himself and his family prior to his injury are intact and vibrantly detailed:

Several months prior to the accident, I was getting along with my wife really, really well. We had been married for just a little less than 11 years when my accident occurred. We truly were happily married. My son was two and a half

years old. Actually slightly more than two and a half years old. He and I had also been getting along really well. In fact, just a couple of days before my accident, I remember thinking to myself how basically successful, by my own definition of success, my life was at that time.

In this account, Robert is describing his experience of himself prior to his accident.

Ontological narratives of being a loving spouse and father are present, as is his perception of himself as having a “successful life” at the time. Recognizing that definitions of success are contextually bound and dependent upon public and meta narratives, it appears that Robert is experiencing “success” largely due to the congruence that exists between his conceptions of success and responses from his social world. In particular, it appears that success for Robert entails being a competent father, spouse, and businessman. He explains:

The night before my accident I was putting my son to bed and he looked me in the eye and he said, “Papa, you’re a big strong man”. And I felt really, really flattered. But it wasn’t just flattered because he didn’t mean it as a compliment. I felt something like flattered. I felt warm and loved and important. I thought, wow, no one has ever called me a big strong man before. I’m actually not big. But the night before my accident he said, “Papa you’re a big strong man”. And that gave me a certain sort of a satisfaction that I’d never thought I’d had . . .

Just prior to the accident, well, Sarah and I really loved each other. We had a very good relationship. In fact, those two statements I just made were so true that I don’t think either of us ever really thought about it. Putting it into words was never necessary because it was something that we lived with all the time. I was certain that Sarah and I loved each other. We were happy with each other and we were happy with our life and happy with our family life. Being two individuals who love each other is something, but being a couple is a different paradigm. It’s the same jewel but different facets . . .

My business, which I started on the first business day of 1996, was doing well. My wife was the chief financial officer and we were successful, again based on my opinion of success [. . .]. I come from an entrepreneurial family. My dad was good at business, so I learned a lot through regular dinnertime talk. I was quite entrepreneurial myself . . .

In summary, I was basically satisfied with my performance as a father, as a husband, and as a business person.

The first account details an interaction between Robert and his son, in which he was told that he was “a big strong man”. This is an excellent example of how Robert’s ideas of success are bound within his social interactions. In this case, his son is commenting on how he views Robert as fulfilling the requirements for a successful father and strong man. It is also a powerful example of how his story of himself as a father, a man, and an important human being was affirmed by his son. Reference to his warm bodily sensations is indicative of the ways in which stories are lived through our bodies (Davies, 2000; Mahoney, 2003), and highlights Robert’s appreciation for this particular story. The other accounts pertain to his wife and business. With respect to his wife, there is a sense of absolute certitude that he was loved and able to take up the narrative of being a loving spouse in a loving relationship. The fact that there were no words to describe it, as it was “something that was lived”, indicates the narrative permanence that this story had for Robert prior to his injury. It was not questioned, and there were no other competing interpretations in the picture. Further, his use of a multifaceted jewel is a telling metaphor of the distinct layered relationships that made up his family, and how precious this was for him. Finally, he describes himself as being entrepreneurial and a successful businessman. Providing the relational and historical background of these talents demonstrates the rich depth of these particular narratives and signifies their importance.

In summary, prior to his injury, Robert’s narrative identity as a successful father, spouse, and businessman were not contested. In fact, the opposite was experienced. He

stories this time as a period of certainty, one in which he easily lived – or to use his word, “performed” – the narratives of what it means to be a competent father, loving spouse, strong man, and successful entrepreneur.

Following his accident, a lack of congruence between his own experience of himself and that of others contributes to great difficulty in his relationships and to his life in general. Differing greatly from Todd’s story, Robert’s accident was not viewed as a setback, from which he is striving to regain his previous and preferred self. Rather, his experiences in the coma state and in the months following waking from his coma, were viewed as valuable experiences that have contributed to, not taken away from, his “authentic self”. In particular, Robert does not consider his post-accident self as fundamentally changed compared to his previous self. Despite breaking bones, sustaining a serious blow to his head, and experiencing permanent physical changes, Robert considers himself fundamentally unchanged. He provides the following metaphor to describe his experience:

One of the best metaphors I can think of for brain injury is the degaussing process that happens on old computer screens. Having your brain injured is like someone pushing a degauss button on your brain. Everything goes wobbly. And like a computer screen after you’ve degaussed it, it takes, I don’t know, a few seconds before it looks the same. It slowly comes into focus and then it’s back to the same computer screen that it ever was. It’s fine. No problem. I believe that my brain injury is like that. After the degaussing is done, fine, no problem. I have some insights, I have some memories, I have some experiences that I’d never thought I’d have before. I have some views of what reality is that I never would have thought before, and I found some poignancy in books that I never would have even read before. But, I don’t think I’ve lost anything.

There is a striking difference between Robert’s account of brain injury and Todd’s. For Robert, despite spending weeks in a coma, months in rehabilitation, having to relearn to

walk and having limited use of one his arms, his dominant story of himself post-injury is that he has not lost anything, but rather gained valuable insights and opportunities that he otherwise would not have had. Thus, he is narrates his accident as something valuable that has not taken away from, but added to his life. This narrative structure resembles the *quest narrative* as articulated by Frank (1995) and is defined “by the person’s belief that something is to be gained through the experience” (p. 115). Rather than injury being a setback from which they are striving to recover, the quest narrative incorporates injury as a valuable experience that contributes to a sense of purpose and meaning. In order to build on our understanding of Robert’s story, it is necessary to examine his experiences in the coma state, in particular the insights he gained and the presence of agency in his story of waking up:

When I was in the coma I experienced a deep and total pervasive peace [. . .]. So coming out of a coma, there is so much that people think is relevant that’s actually nonsense. That is complete nonsense [. . .]. For example, the clock is so incredibly artificial. It’s 100% artificial. Time itself is just a social construct. Time has no existence of it’s own . . .

Once you’ve been in the pervasively beautiful and peaceful coma state, it’s difficult to be non-comatose. Believe it or not, I remember manifesting in my own body. I remember occupying my body and that was difficult. Occupying a body is so limiting. Your body is so limiting. All you have is it. In the coma state you are everywhere and everything . . .

I allowed myself to come back. I felt that going back was optional. Or coming back, you might say, was optional. The love of my wife had a real longing quality to it. I could tell that she had a longing, a profound longing for me in the love that she was feeling for me at that time. I was somehow aware of this longing feeling. She loved me all the time, but the longing was profound and so, I exercised the choice to come back because I felt compassion for her longing for me . . .

These small excerpts are immensely helpful in understanding Robert’s experiences upon emerging from his coma. They appear to have provided him with new and important

narratives that influenced his experiences of recovery. In particular, his realization regarding the relativism of concepts such as time, and his experiences of peace and omnipresence, which he contrasts with the limitations of his physical body. The story of a separation between his self and body is a significant component of his narrative. Unlike Todd's story, which focuses on restoring the self through mending the body, Robert's story of recovery begins with wholeness and his physical body is considered limiting and restraining rather than the source of his recovery. Further, his belief that he had a choice in returning and that "coming back" was a compassionate response to his wife's longings, not his own longings, is another important difference from Todd's narrative structure.

Robert further explains his decision to "come back":

Robert: While in the coma state, there were so many things that I just didn't care about. For example, the nurses would be asking me what country I live in and what year it was. Frankly, I couldn't care less. Yes, I didn't know, but it was not important. It just did not matter, truly didn't matter. Anyway, in order to come back, I had to permit myself to acknowledge time and to take time seriously so that, (a) I could get the correct answers on the mini-mental and (b) I could be considered worthy of integration into my pre-accident life. And frankly, some of that I just didn't want to do. I still, as you can tell, still consider a lot of it irrelevant crap. However, we have to demonstrate to others sufficient buy-in to the irrelevant crap so we can be a functioning member of society.

Dave: That's so fascinating. So probably people were seeing this new perspective as signifying your brain injury.

Robert: Yeah, anti-social, possibly psychotic.

Dave: Whereas where you were coming from was this profound spiritual perspective.

Robert: Yeah, yeah, yeah. Actually I think mystical is a better word than spiritual but spiritual will also apply. Yeah, so there is a lot of buy-in. So I was given the blessing of so much removal from all that buy-in that I could see it kind of from the outside and it was reluctantly that I re-entered the full package buy-in.

This conversation highlights the importance and value that Robert places on his experiences in the coma state, as well as the agency present in his narrative structure

post-injury. Rather than desiring his physical body, he reluctantly chooses to re-enter into the limiting world he had left behind and “buy in” to social conventions, so that he can be considered a legitimate citizen. However, also present is the incongruity with regard to how Robert was narrating his experience and how the nurses were. For Robert, he was in a mystical state; for the nurses, interpreting his actions according to the medical discourses available, he was demonstrating signs of severe brain damage. This points to how the stories available to interpret a situation have serious implications for Robert’s own experience, even if they are not congruent with his own story. Furthermore, this situation supports the findings of Cloute et al. (2008) regarding the tendency for medical model referencing by expert professionals to restrict and diminish competing interpretations held by brain injury survivors. The fact that Robert is using terms such as “anti-social” and “psychotic” point to his familiarity with medical model narratives and how, in this case, he is drawing from less predominant and recognizable narratives to interpret his situation.

As mentioned above, the incongruity between Robert’s own experience of himself and that of others would lead to great difficulty in his relationships, particularly with his wife, Sarah. According to Robert, the first such instance of conflicting stories occurred in the telling of his “waking up from the coma story”:

Robert: My waking up from the coma story is a different one from hers. It was a source of distress for her. Almost every time I would attempt to tell my “woke up from the coma” story, she would just roll her eyes and exhale and such. It was really upsetting for her because she was absolutely certain that I was awake from the coma prior to Thursday, August 17th. However, to my awareness, I only have these little bits and pieces of lucid moments. I was just visiting.

Dave: Wow! So why do you think she was frustrated that your stories are different?

Robert: Well, I think for one thing, I would tell my “woke up from the coma” story in a way that reflected its grandness to me. And she saw no grandness in it at all. Yeah, there was nothing grand about it at all to her. It was just another day of me demonstrating lucidity. To me, it was, I’m waking from the coma. So to me it’s a grand story. To her it’s not. So it is the big contrast that I think it is a source of distress or discomfort for her. . . .

Another element of frustration for her about that story is that she has no ownership of that story. It’s my story. My “woke up from the coma” story. The only person I interacted with was a nurse. So she has no ownership of it. She has no direct experience of that vignette of my life. So she can’t own it. As far as I know, she still can’t accept that it was a grand, massively significant experience to me that I was finally coming back from the coma.

Dave: To you, that was a pivotal and key moment in your recovery?

Robert: Oh yeah. Waking up from a coma and knowing that you’re awake from a coma, that’s a big deal. But to her it was neither.

This conversation highlights a significant disruption in Robert’s post-injury narrative identity. Prior to his injury, his preferred and important stories about himself (e.g., successful husband, father, business person) were acknowledged and affirmed by his family and community. However, in this instance, his spouse does not acknowledge a story that Robert believes to be a vital aspect of his post-injury identity. Interestingly, the language Robert uses in relating these experiences assumes a narrative character. Phrases such as “my coma story”, “the vignette of my life” and “she has no ownership of it”, suggest that Sarah has no way to write herself into this new and profound storyline. This dissonance between Robert and his wife continues to be a major problem. Robert believes that Sarah is unable to accept him as the “authentic Robert” leading to another source of concern:

I believe that to this day, Sarah, remains fundamentally challenged in certain ways in accepting me as the true, real, authentic Robert, her husband. I believe that for her own reasons, mainly emotional and psychological, she denies me the authentic Robert husband status. I think that she regards me from certain angles as an inauthentic Robert. The guy who came out of the coma isn’t now, and never has been since he came out of the coma, truly her husband. Yet, I’m 100% totally the

real thing. She just can't allow herself to think of me as anything other than a counterfeit and a bad wrong man.

In this account, Robert expresses his frustration regarding Sarah's reluctance to accept him as "the authentic Robert". Unlike Todd, Robert does not experience his injury as taking away anything from his "authentic self", the self that exists for him beyond his physical body. Yet, he is confronting a story of himself as not being authentic and instead "counterfeit and a bad wrong man". Interestingly, he draws on individualizing public narratives to explain why Sarah is unable to acknowledge him as authentic, and locates the problem within Sarah's psychological and emotional makeup. However, as previously demonstrated, it appears that Sarah has not taken up Robert's narrative regarding his insights from his coma state and particularly the story of his "self that exists beyond his body". Rather, it appears she has been steeped in particular narratives that lend themselves to narrating Robert quite differently. Robert explains:

When I got out of the hospital, everyone kept asking Sarah if it was really me. Like, "Is it him? Has he changed?" The nurses in particular kept asking her this. At the time, she was, like, "Yeah it is him. Of course it's him. He just woke up from a coma and we're listening to music he loves, and he recognizes me and his son. Of course it's him". Over time, though, things started to change. My physical wounds were mostly healed, except for my arm, which will never have full mobility. We were trying to rebuild our business. I was definitely more tired than usual and feeling a lot of pressure to fulfill the title of "my husband is back and healthy". But it takes time to rebuild a business. One needs to make decisions that have calculated risks attached to them. My wife wouldn't let me do anything that in my mind were essential to saving the business. She was told that my judgment could be impaired because of my injury. I was also aware that this may be the case, so I took great strides to seek out business advice and have people I trusted cross-check my decisions. I wouldn't want to be the fool who doesn't recognize he is a fool. Despite their support, she still declined my suggestions. Yet, she was still feeling mounting frustration that things were not progressing . . .

In addition to the narratives encountered at the hospital, Robert describes how similar narratives were encountered with counsellors in the community, and how these came to restrict his identity:

She went to see this counsellor who reinforced the idea that I was permanently damaged and diminished, someone who will never be the man she married, who will never be the man she fell in love with. She's got this impersonator living in her husband's body who answers to his name and wears his clothes and who thinks he's the same person but who really isn't. She collected a bunch of worst-case scenario stories, things to watch out for. And honestly, I'll tell you in a variety of contexts, I believe that if somebody's watching for something, if they really are watching, they are far more likely to find it than if they just sort of stumble upon it. So, once she had this idea that I was not the man she married, it was all downhill. . .

There were only two negative ways of seeing me. Like Side A and B of a record. There was no Side C.

These excerpts point to a number of public narratives that appear to be constraining Robert's narrative identity and contributing to a particular telling of him as a damaged and deluded person. First, the nurses' repeated queries regarding whether or not he is the "real" Robert, marks the emergence of the narrative that he may not be authentic. As mentioned in the literature review, a large body of research exists exploring "personality change" following acquired brain injury. Largely influenced by medical discourses locating personality solely in the brain, such changes are thought to be permanent and unavoidable negative consequences of ABI. These ideas appear to be perpetuated by the counsellor and led Sarah to seek out evidence to support this story. In addition, particular narratives regarding the progression of his business are also present and interacting with medical narratives, specifically expectations for Robert to get his business on track and to fulfill his role of being "back", accompanied by suspicion regarding his ability to make sound decisions. Clearly, Robert is aware of his potential for judgment errors. However, it appears he is not recounting these experiences as an indication of his diminished status.

In summary, Robert appears to be struggling to have his preferred identity acknowledged and experiences little room for alternate narrative possibilities beyond his diminished status.

Another important aspect of Robert's post-injury narrative is that he too is drawing on medical discourse, but in his case to substantiate his "authentic status". In particular, he describes the numerous psychological tests that he underwent and how, much to the disappointment of his wife, he was cleared of any substantial damage that could render him a diminished man. He explains:

Not too long after my release from hospital, partly at Sarah's urging, ICBC financed a full neuropsychological exam. And the full exam concluded, much to her disappointment, that I am, quote, "of superior intelligence". My IQ is 142. My IQ wasn't the only conclusion that it drew, but that was the most upsetting to Sarah and, frankly, it was the most buoyant to me and the most self-vindicating to me. My IQ is in the superior range. But there were other aspects of the neuropsych report that basically cleared me to run my business, that cleared me to be a father to my son, cleared me to be a husband to my wife, cleared me to be a voting citizen, and cleared me for all the basics aspects of being an adult functioning in our society that I had pre-crash. There were cautions about multiple auditory distractions and a couple of other things having to do with spatial organization. Although, I actually still did above average on spatial organization, but for someone of my IQ range it was lower than expected. So across the board all of my tests came out favourable, none of them showed any demonstrable weakness, they were still in what is considered the normal range.

Robert is drawing on psychological and medical narratives to substantiate his claim to normality and to support the taking up of his preferred story as a business man, father, spouse, and citizen. The importance that he places on these psychological tests in legitimating his status as a functioning adult resonates with Nikolas Rose's (1990) insights regarding the power that psychological testing has played in the West with regard to the creation and maintenance of the normal and abnormal *self*. For Robert,

drawing on these narratives are a helpful means to legitimate his desire to be regarded as normal. It also demonstrates how both Sarah and Robert are drawing on different medical and psychological narratives to support their particular and divergent interpretations of their situation.

It was in the midst of this struggle for his preferred identity that Robert, along with his wife and son, enrolled in the MFP. The following section explores some of the shifts in identity that Robert describes as a result of his involvement in an outdoor, activity-based, family program.

Shifting identities: The program as a context for preferred ways of being.

The previous section focused on Robert's narrative identity both prior to and following his injury. Emphasis was placed on identifying the main narratives present in Robert's story and illuminating the unfolding struggles surrounding identity. This next section explores how Robert's involvement in the MFP contributed to additional shifts in his narrative identity. As with Todd's story, the intention is to create space for sharing the multiplicity of identity conclusions possible for Robert and how some of these alternate stories were made available and served to challenge the "problem saturated stories" (White & Epston, 1990, p. 16) he was encountering outside of the program.

The program as a context for the creation and witnessing of a "Side C".

When Robert was asked how his experiences in the program contributed to his life, he immediately turned to talking about his son. He made it clear that despite the differences in how his wife views him, his relationship with his son had not succumbed to the negative perceptions she held. Undoubtedly, his preferred narrative as a loving and

competent father was threatened, and he explains that the program facilitated positive interactions with their son that were witnessed by a supportive community. It was the witnessing aspect that played the most important role in promoting his preferred story:

Robert: I have prepared some thoughts on how my family process has unfolded, since my brain injury, in the context of the ABI program. One of them is that my son can share the experience of having fun with his papa and with other people. So there have been other people there to witness it.

Dave: Can you say more about why the witnessing was important?

Robert: Well when I say the word witness I mean, my son knows that there are other people who have also seen it. You know what I mean? It's not just an experience on his own, it's not just an experience that maybe he's imagined. It's an experience that he's shared with a bunch of other people. It makes it more powerful.

In this conversation, Robert highlights the importance for both himself and his son that there is a community to witness their experiences of spending time and having fun together. Although being together is not uncommon for Robert and his son, what is being acknowledged is the social recognition of their positive experiences together. This is not surprising considering the dominant narratives that Robert describes occurring outside of the program. Having people witness him having fun with his son supports his desire for a "Side C", one aspect being the narrative that he remains a strong, loving, and competent father. It is comforting for Robert to know that his son has people who have witnessed their time together. In doing so, it appears to solidify these preferred narratives making it more difficult for them to be replaced by those that make him out to be otherwise.

Another aspect of the program that pertains to his preferred narratives of fatherhood are the opportunities afforded to do things that he had hoped to do with his

son, but were delayed due to his accident. Interestingly, Robert makes it clear that it is not that he “could not” do these things, but rather how they were facilitated in a more timely and desired fashion:

Robert: Something else that I think is important about the family togetherness days is that my son has had opportunities to do some things with me that we might not have done if it wasn't for the program. If the program hadn't been created then there are some really valuable experiences that from the sort of injury-recovery perspective, I think my son really kind of needed and that need might not have been met so effectively or in such a timely way had we not gotten involved in the family togetherness days. Such as spending time together outside, going canoeing, kayaking, and hiking. I went canoeing when I was a boy with my father and I remembered the experience and liked it and it was one of the things that I sort of had on my agenda, so to speak, in terms of things to do with my own son.

Dave: So the program facilitated the achievement of some of the hopes that you had for you and your son?

Robert: Yeah, after my accident occurred, I was so very concerned about rebuilding my business and so very concerned about making us financially viable again and rebuilding my strength and flexibility in my body. It might have taken, I don't know how much longer, but it probably would have taken, let's just say considerably longer, to use a vague term intentionally, before my son and I would have gone for significant nature hikes or climbs or things of that nature. It's so wonderful that my son and I have shared taking a good long walk through the forest. Such as we've done at East Sooke Park.

As laid out in the first part of Robert's story, his narratives pertaining to being a successful father were not contested pre-injury. As is often the case with serious injury, following an accident many of the hopes and means for living out preferred stories have to be set aside, sometimes indefinitely. However, Robert describes how his experiences in the program facilitated a reclamation of some of these hopes, particularly with regard to fatherhood and spending time outside, as he had with his father. Robert does not situate this experience as being completely out of his reach, but rather that they were

facilitated in a more timely and desired fashion, minimizing disruption to desired fatherhood narratives following injury. Thus, his involvement in the program encouraged a sense of narrative congruence with regard to his pre-accident scripts as a father and his current situation. His insistence that he “could have” done such activities, signifies the agency present in his current narrative and his reluctance to describe himself as having lost anything post-injury.

In addition to having preferred narratives surrounding fatherhood witnessed and facilitated through the program, Robert also expresses the program’s importance in addressing his identity struggle with Sarah. The following conversation summarizes this experience:

Robert: I think our involvement in the program gave my wife, well, an opportunity to witness that I’m not just some broken man. [Laughs] But I’m a guy who can have fun with his child. I’m a guy who can go kayaking or go hiking or whatever for a full day and not become grumpy. I figure when you’re out in the fresh air and you can hear your child laughing, and you can see your child laughing, together with his father, then you can’t diminish the father as much as maybe I was describing she wanted to. You know what I mean? So I think that the family togetherness days created a kind of veracity for the family life that my son innocently expected and that I knew was possible. But which my wife might not have acknowledged even the possibility of unless she could be, basically a third party to it. There is Rob having a really good time in a kayak with our son and she’s watching it. You know what I mean? So I think a lot of the concepts that she got about a brain injury survivor from her counsellor and other people had the opportunity to be proven not true. [Laughs] You know what I mean. I demonstrated to her without even having to try, that I could do the things that we do on the family togetherness days and not fulfill all the fears that she developed about all the horrors that can occur with a brain injury survivor.

Dave: So being in the program was a useful way for you to create more possibilities of who you were.

Robert: Yes, thank you. Perfect summary. So I think that the program created another list of possibilities for my wife to perceive me, rather than just fearing the worst of the anger issues. The worst of the verbal abuse issues. The worst of this, the worst of that. You know, bad memory, anger management problems, forgetfulness, really poor decision making, all with confidence in myself to be a great decision

maker and stuff. That would be the fear, right? “My husband is the worst fucking decision maker I’ve ever met in my life and yet he thinks he’s just as competent a decision maker as he was before. And, gosh darn it, he still carries the same ID and looks the same when he look at himself in the mirror. Oh migawd!” So I’m just saying that I think Sarah had created basically an inventory of things to fear and because she had this inventory of things to fear, she was watching for them. And when she saw something even resembled one of the things on her inventory of things to fear in her, inside herself if not out loud she’d go “Ah hah! My husband is guilty of being one of those compromised damaged people and I’ve seen it with my own eyes now that I’ve been watching for it 24 hours a day for weeks.” The point is that by being in the family togetherness days and seeing my child have fun with me, seeing her child have fun with her husband, and by seeing us eat and get along competently and not get into fist fights or shouting matches or make terribly bad decisions or whatever, provided an opportunity for her to witness that the worst case scenarios don’t really happen, with me anyway. Instead, by her having those experiences it facilitated, the undoing or at least the slowing down of her inferiorizing of me. She could witness that I was a competent adult, relating to people in a competent way, rather than in a diminished way.

Clearly, a major source of distress with regard to Robert’s identity was occurring in his relationship with Sarah. His experience of negative identity conclusions being placed on him through particular narrative lenses constantly threatened to portray him as a diminished man and father. The program appeared to create a novel context from which Robert could assume preferred narratives of fatherhood and of personhood and have these experiences witnessed by his wife and peer group. For Robert, this was a profound shift, as it allowed for the creation of a valuable forum in which he could challenge identity conclusions he felt were undeserved and in so doing, facilitate the possibility of a “Side C”. That his wife was able to witness this side made it that much more powerful.

Summary of Robert's Story.

There were other aspects of the program that contributed to further shifts in Robert's narrative identity. For example, he explained how spending time in nature and participating in adventure activities facilitated a sense of assurance and confidence that preferred stories about himself as a nature lover and adventurer were still possible. He also mentioned the importance of seeing other people with brain injuries succeed at adventure tasks and interact positively with their families as a powerful and reassuring alternate story to the those that depict brain injury as indicative of failure or of being diminished. Unfortunately, examining these other areas in-depth falls beyond the scope of this particular analysis. The purpose of this section was to highlight how Robert's experiences in the program facilitated a shift towards an alternate story of himself as a father and competent adult and to demonstrate the importance of the social dimension in having these stories acknowledged. Recognizing the lack of social acknowledgement he was experiencing following his injury with regard to being accepted as the "authentic Robert" and a loving father to his son, it is no surprise the program was experienced so positively by Robert. Curiosities definitely loom regarding Sarah's experience of the program and what her version of the story would be. However, the point is not to "solve" their conflict, nor to determine who is right or wrong. Rather, it is to highlight the importance of narrative structures and their social contingency both in shaping identity and influencing the availability of preferred stories.

Diane's Story: No one gets it! The pressures of being a caregiver and losing so much!

Diane's story is the final exemplar being used to explore and illuminate the numerous shifts in identity that occur for survivors of ABI. Again, attention is being placed on exploring some of the main narratives and particularly the changes that occurred following injury and involvement in the MFP. Although each story presented is highly unique, their social contingency and the role that narratives have in the construction of identity will continue to be evident.

Diane's story represents that of the caregiver, a different but vitally important perspective of what being a survivor of an acquired brain injury entails. In 2004, her husband sustained a life-changing brain injury. Diane tells the story of his injury with trepidation. The pain and memories are vivid. She recounts that he was in an altercation with the police that resulted in him falling to the floor handcuffed. With no way to protect himself, he sustained a serious head injury. Following her husband's injury, Diane states that her world was profoundly changed. She offers the following accounts in an attempt to express the enormity of her situation:

The extent of change that my son and I underwent following my husband's accident is akin to picking us up out of here and moving us half way around the world. Like, it is just, it's so huge that I can't even, express how huge it was . . .

When the injury first happens, you go through crisis and you're just like on auto-pilot and then they come home and the world falls over. It just cracks right open.

The magnitude of change that Diane experienced following her husband's injury was so all-encompassing that attempts to describe it seem beyond words. Instead, she draws an image of her and her son being transported across the globe, and having the world topple over and crack. These short excerpts highlight how Diane's experiences of injury entail

being thrust into a new life, one in which the very fabric that provided her with sustenance (her world) had toppled over and cracked.

Without diminishing the numerous ways in which Diane responded and resisted the constant threats to her own and her family's preferred identity, undoubtedly her pre-accident story took a dramatic and unexpected turn for the worse. Over a period of a few days, her "comfortable life" and identity as a spouse, co-parent, employee, student, adventurer, and friend shifted to her being the lone life support system and caregiver for her husband and two and a half year old son. During conversations with Diane, it quickly became evident that following the injury her life shifted to one of chaos and isolation. She recounts that few people understood the gravity of her situation and that her identity had been reduced to that of caregiver. She discusses her own experiences of loss of self, and the importance the MFP played in reclaiming her preferred identities. The following analysis explores these points in more detail.

Diane describes the months following her husband's injury as isolating, frightening, and highly unpredictable. Unlike Todd and Robert, her husband's injury did not warrant an extended visit to the ICU. Instead, he was in hospital for a short time and despite recommendations that he stay, discharged himself and returned home. Diane explains that a common response for people with a brain injury, not involving extensive physical trauma, is for the person to not recognize the extent of their injury and refuse medical treatment. It was at this point that Diane knew something was wrong, but had no one to turn to, including her husband and family. She explains:

Diane: When my husband was discharged from the hospital, he came home and that was it. There were no doctors, there were no nurses, there was no support for me along the way.

Dave: Wow, you were totally just left on your own.

Diane: We were just hung out to dry. Like he slipped through the cracks and he shouldn't have. There is no way that he should have slipped through the cracks like that.

Dave: Yeah I wonder how that happened.

Diane: I don't know. There just wasn't place for him at the Gorge outpatient rehabilitation and there was no in-between.

Dave: Was there nothing for your family during that time?

Diane: Totally nothing. I think it has to do with brain injury being invisible. It's hard to notice because he walked and talked and looked like he was fine and he was able to act like he was fine in public. So everyone thought he was fine. And even the doctors thought so. It took a lot of advocating on my part for his doctors to even realize that he had a mental illness that was so severe that he was totally gone. Like when he finally made it into the Gorge outpatient rehab program, he was having psychotic episodes and they didn't even know until I phoned the social worker every day for two weeks and demanded that something is wrong with him.

Dave: Wow!

Diane: Even to the point where his family and his friends thought that it was all in my head. I was the one who was sick. That it was me.

This conversation points to a number of important factors contributing to Diane's post-injury story of being isolated and positioned as *the problem* following injury. In particular, her community did not acknowledge Diane's narrative of being in crisis and having her "world toppled over". Instead, her husband's physical body being relatively free of visible indication of injury and his ability to uphold his previous self status with his friends and family, led to assumptions that everything was "fine". This situation points to particular public narratives surrounding injury, society, and the body. It suggests

a particular understanding of injury as being a physical occurrence, one that resides strictly in an individual's body and only exists and deserves recognition when it can be viewed in this manner. This rendered the concerns of Diane and her son as invisible, even though they faced immense challenges.

Despite Diane's deep concern and knowledge that things were not okay, this dominant story of everything being "fine", upheld by those around her, had tremendous influence on her own narrative identity. She explains how she became solely responsible for providing the necessary caregiving for her family, and how caregiving came to dominate her life and identity. She also recounts the tremendous uncertainty and overwhelming fear for her own and her son's safety. Moreover, attempts to reach out for help were viewed as an indication of her own inability to cope and thus internalized as her problem. Diane expands on how frustrating and isolating it was that so few people understood her situation:

There were so few people that I could turn to who understood my situation. Like how frustrating and hard and exhausting it is. I didn't have anyone really to talk with . . .

I've been to counsellors who just didn't get it at all. They wanted to, but they don't. I think people know that it's an injury and it's very impactful and it changes lives, but the depth to which that happens is just not grasped . . .

In addition, she provides insights on the uncertainty, fear, and isolation in the aftermath of the injury:

There is so much unknown at the beginning. I was totally exhausted and stretched . . .

Waking up and not knowing who was going to come down the stairs was really stressful. Like you didn't know if he would be in a good mood, in a bad mood, if he'd be tired, or if he'd even be able to look after our son when I had to go to class. The unknowns were unreal and overwhelming. It was crazy . . .

We were totally stuck in a major rut. Leaving the house and doing the things we used to for fun were next to impossible. It was hard enough to make it through a day at home.

For Diane, life following her husband's injury was chaotic and isolated. A dramatic change from the structure, certainty, and community she experienced before. Due to her husband's lack of serious physical injuries, it appears he was not regarded by those other than Diane in the same way as Todd or Robert, and instead everything was assumed to be "fine". An important point to add is that he was experiencing common symptoms associated with a brain injury such as fatigue, memory loss, and concentration problems. These physical symptoms were acknowledged by Diane's friends, family, and medical personnel. What was overlooked, however, were the changes associated with his day-to-day interactions, involving anger outbursts and unpredictability, as well as his compromised ability to maintain previously held conceptions of reality. Had the medical community and Diane's peers recognized these changes, perhaps she would have been offered different narratives to navigate her situation. Instead, it appears she initially held tightly to a restitution narrative, a belief and hope that things would return to how they were. She describes her experiences during this time in more detail:

I think I stuck to the hope that my husband would heal and that we could continue being the family we were for as long as I physically could. But it got to the point where physically I was not able to be healthy and keep that hope at the same time. It was like, I don't know, destroying who I was and, what I wanted from life. It took over reality and threatened all the things that I valued for my son and myself.

This account highlights how Diane was attempting to maintain previous narratives of her family, notably those narratives of her marriage and family unit staying together. Thus, hope at this stage for Diane was based on a vision of their life returning to how it had been. Also, it appears she is describing her own experience of *loss of self*, a phenomenon only recently gaining attention in the ABI literature regarding caregivers (Landau & Hissett, 2008). Diane provides additional insights on how the public narratives involved in being a caregiver, in particular a spouse, contributed to feelings of being stuck, and to an erosion of her own sense of self:

Diane: As a caregiver, you ignore your own needs for way longer than you should. It's like you know your line is here. You draw your line in the sand and say to yourself, okay I won't cross that line. And then six months later you realize that your line is way on the other side of the beach. You crossed your line a long time ago. I desperately wanted to [pause]. . .

Dave: To make a change.

Diane: To know that it was okay to change. It was okay to make that choice. That it wasn't that I was a bad person. I wasn't letting anybody down. I wasn't hanging my husband out to dry. That it just was a choice that I had to make for both myself and my son. But there was so much guilt and pressure regarding the commitment you made to not leave the person who is injured. Even taking a bit of time for myself was viewed as selfish. Like, I was selfish for not helping my injured husband.

Diane is describing specific public narratives involved in her post-injury identity as a spouse and caregiver. In particular, she is speaking to the social scripts involved with being a "good wife" and "good caregiver" and how her desire to make change within these narratives perpetuated experiences of guilt and shame. As mentioned above, Diane had to advocate in order for her husband to receive the medical attention she felt he needed. For her family, this was a vital step in facilitating her husband receiving services

and gaining recognition for the direness of their situation. It also cemented her identity as a caregiver. Increasingly, it became difficult for Diane to leave her situation, as decisions to do so were viewed as her choosing to abandon her injured husband. Thus, Diane was now interacting with both marriage narratives ('til death do us part) and caregiver narratives (must help him heal), creating a highly restricted and immensely difficult situation:

In those first few years I really felt stuck and trapped, and that's the worst place to feel. I desperately wanted to dig myself out, but also know that it was okay.

Our family was really stuck in not doing anything. Like, it was just so hard to get organized to do anything.

It was in the midst of Diane's struggle to maintain her previous and preferred identities that she decided to enroll her family in the MFP.

Shifting identities: People who “get it” and discovering her preferred self.

Reflecting on the program, Diane expresses gratitude and hopefulness with regard to an opportunity to encounter something new. Especially being with the other caregivers who really “got it”. The following accounts describe this experience:

It used to be that my husband and I coordinated activities together and after the injury it was all me and I just didn't have the energy left over to do that. It was easier to just stay at home than it was to plan to have to go somewhere. And so the program forced us to get out and do things and that for me was big because I was feeling trapped to begin with . . .

I think the biggest thing for me was meeting the other moms who I just understood and I had that connection with right away. It was just incredible to know that there is somebody who could understand how I was feeling without even having to explain why I was feeling that way. Who just got it, you know? They knew how I was feeling and how frustrating and hard and exhausting it is.

Mahoney (2003) explains that a fundamental component of change processes involves the introduction of manageable novelties. This definitely was the case for Diane upon joining the MFP. Once she was able to leave her house and encounter something different, change became possible. Further, being with the other caregivers was a welcome experience for Diane. As described, her post-injury experience involved encounters with people who were unable to grasp her situation, resulting in her being cast as the source of her problems. Thus, being with people who understood allowed for new narrative possibilities. Diane explains that she was able to challenge undesired aspects of the caregiver identity and gain valuable insights on her situation:

Being with the other moms at the program was the start of something big. I was able to realize that taking time for yourself or thinking about yourself is not being selfish, it's just looking after myself. Having that repeated every month for the program allowed it to finally sink in. Oh, wait a minute, I can do this on my own. It made me realize things like, that I wasn't happy and I wasn't who I was. Like, I lost who I was. I was always sad and I was always tired and I didn't feel intelligent anymore and I didn't feel pretty and attractive anymore. And realizing that that's how I felt was huge.

This account marks a significant narrative shift for Diane. Being in a supportive group presented alternative stories regarding caregiving and self-care that, with time, came to replace less desired ones. Viewing her life through these alternate narratives facilitated a recognition that her current identity was not congruent with who she desired to be, and that she had “lost” her preferred self in the aftermath of her husband’s injury. From a narrative perspective, it appears that she was able to reinsert herself into her own story and from this new vantage point, the dissatisfaction with her current identity became visible.

According to Diane, being in the program provided her not only with alternate narratives of caregiving, but also opportunities to reclaim and rediscover aspects of her preferred identity that were not previously available. In particular, she described narratives surrounding being a nature lover, a mother, and a strong person. The following accounts are useful in understanding these shifts:

Nature Lover

I've always found nature to be really calming and peaceful. For me, the ocean and the forest are just places that I've always gone to and I feel really comfortable with. In the aftermath of the injury having time to spend in nature was non-existent. So being able to reconnect with not just nature but reconnect with people and our family in nature was huge.

Mother

As a parent, I really wanted my son to not feel different. By being with the other families and having him see other people interact with their fathers who also had brain injuries and that he was not alone or terribly different was huge not only for him, but also for me as his mother . . .

I really believe that it is important for my son to play and be in nature. As a parent, I want to provide him with opportunities to play, roam and time to explore out there. So being in the program and having activities like the scavenger hunt and stuff that used what nature has to offer to engage kids was really good and really cool for me as his mother.

Strong person

I found the adventure activities super helpful for me. Like the wall climbing thing and the kayaking thing. I love the whole program, but those parts were my favourite activities that we used to do and I just have not done them since his injury. They also allowed me to remember that I am a strong person and that I can accomplish things. When I am in the thick of my family life, I never have a chance to see myself from a distance, I mean the strengths that I have. But the adventure activities really allowed for that. Although some of them were scary at first, once I made it through, it felt so good! It was reassuring that I will make it through this too. They were my favourite parts of the program.

These accounts highlight a number of important narrative shifts for Diane. First, she acknowledges her previous affinity towards spending time in nature and specifically how she experiences nature as an important, peaceful, and restorative place. This is a significant contrast from the chaotic and stressful story of her home life. She also mentions the value of having her family and friends present in nature with her. As with the discussion of Robert, this speaks to the importance of social recognition in validating and substantiating alternate narrative identities. With respect to Diane, having people present to witness her as a “good mother” and “strong person” was critical. Also present in these accounts is the inclusion of her hopes for her son and ultimately her identity as a mother. Mentioned throughout her interviews were her concerns that she was not living up to the “good mother” narrative. However, during her involvement in the program there were opportunities for her son to play and be in nature, to feel less isolated and different. As a result, she expresses congruence between her hopes for her son and her ability to provide such opportunities for him, facilitating her position as a “good mother”, and challenging the “bad mother” identity. Finally, Diane relates the importance that the adventure activities had in reclaiming previously held identities and specifically repositioning herself as a competent and strong person. In so doing, these preferred narratives could then be transferred to her situation at home and contribute to the alternate story of her actually making it through this difficult situation.

Summary of Diane's Story.

The sharing of Diane's story presents a valuable and often overlooked perspective of being a survivor of ABI. The above analysis illuminates the narrative landscape Diane encountered following her husband's injury and how it threatened to colonize her preferred identities and position her as the problem. Specifically, narratives surrounding marriage and caring for her injured spouse were highlighted. The analysis also demonstrates the relational processes involved in the construction of Diane's post-injury identity and how her involvement in the program facilitated a rediscovery of her preferred identity. Interestingly, narratives of hope for Diane seem to have shifted following her involvement in the program. Rather than hope being tied directly with her husband's recovery, the presence of personal agency makes an appearance in the latter part of her story. Thus, there was an insertion of her "self" into her own story, instead of a yearning for and reliance upon her husband's recovery.

Including the caregiver perspective is an important contribution to this exploration of life following ABI. Critical issues pertaining to caregiver identity disruptions, safety, and the public narratives that promote experiences of guilt and shame while restricting possibilities for change, were raised. Most importantly, the complexity, confusion, and frustration often involved in navigating recovery for survivors has been emphasized.

CHAPTER 5: DISCUSSION

This research examined the shifts in narrative identity demonstrated in the stories of three people who had participated in a unique multi-family outdoor adventure program (MFP) for survivors of acquired brain injuries (ABI). In doing so, it sought to illuminate the diversity of narrative identities associated with the narrow and socially constructed categories of *brain injured* and *caregiver*. Recognizing the possibility of preferred identities directed this research toward attending to the experiences in the MFP where desired shifts to such identities became possible. In doing so, valuable insights regarding the reclamation, rediscovery, and reconstruction of preferred identities were illuminated.

In this final chapter, reflections pertaining to (a) the importance of social contexts, (b) nature and adventure, and (c) the centrality of hope in the construction of preferred identities will be discussed. Recognizing the numerous interpretive paths available, it is hoped that these reflections will permit engaged readers to acknowledge their own interests as valuable lines of inquiry that may lead to additional insights regarding shifts in narrative identity. In addition, recommendations for further research and practice in the areas of ABI, identity, and adventure therapy will be offered at the end of each section.

Social context and the construction of preferred identities

The importance of the social context with regard to narrative identity was apparent in all three stories. For Todd, interactions with medical narratives in which his relationship with progress was not acknowledged led to serious threats to his relationship with hope and dignity. Robert experienced a similar situation when his nurses and subsequently his wife did not share his rendition of his coma story, leading to high levels of discomfort. He describes how the MFP allowed a social group to witness his preferred

stories as a father and competent man, contributing to the possibility for a “Side C”, a welcome alternative to the limiting narratives restricting his identity. Finally, Diane’s story demonstrates how a failure by her family and the medical community to acknowledge her story of her husband’s injury, resulted in her being cast as the problem. Through her involvement in the program and meeting those who “got it”, she was able to construct a different relationship with herself, one in which she was able to reinsert herself as a main character in her life story.

In each of these stories, there is recognition for the importance of the social contexts in constituting one’s narrative identity. It is not sufficient to know your own story. Rather, having your story accepted and acted upon by your social world appears to be a key aspect in negotiating a preferred identity following injury. Intriguingly, this appears to suggest that the MFP was a unique social context offering narrative possibilities beyond the restricted narratives available outside of the program. Specifically, it provided the participant’s invaluable opportunities to move beyond their problem-saturated identities and reclaim, rediscover, and reconstruct preferred ways of being in the world.

These findings are congruent with the literature presented previously, as they demonstrate how certain social contexts can perpetuate identity disruptions and increase levels of discomfort for survivors. In particular, these results support the work of Nochi (2000) and Cloute et al. (2008) who both suggest that successful reconstruction of identity following injury relies on interpersonal exchanges that enrich rather than challenge preferred self-stories. This also supports Clandinin and Connelly’s (2000) inclusion of the dimension of *place* as a critical area of interest in narrative inquiries.

In addition, recognition of the social context resonates with the work of social constructionists and narrative therapists. Social constructionists both recognize the co-constructive basis from which reality is negotiated and rendered possible (Gergen, 1999), and are also intimately familiar with the possibility for self stories to be constructed in deficient, defective, or problem-saturated ways (Gergen, 2007).

Likewise, narrative therapists strive to challenge negative self-accounts by facilitating re-authoring processes through attending to alternate stories. As Freedman and Combs (1996) explain, narrative therapists focus on facilitating situations that serve to privilege alternate stories and help keep them alive by documenting, witnessing, and performing them in order to make them thicker and more connected to past, present, and future stories. According to Hogan (1999), narrative therapists “emphasize the importance of audiences for preferred stories, of local subcultures that construct and circulate the alternative knowledge that provides new lenses through which to interpret experience, both individual and collective” (p. 24). Examples of narrative practices that intentionally utilize the presence of a group of people in order to support the construction and proliferation of a person’s preferred identity include outsider witness groups, (White, 2007), definitional ceremonies (Myerhoff & Kaminski, 1992), and reflecting teams (Freedman & Combs, 1996).

Evidently, the MFP served as a unique local subculture in which the preferred stories – and thus preferred identities – of Todd, Robert, and Diane could be enacted and enriched. Additional research is warranted to investigate the merits of a narrative therapy approach to reconstruction processes following ABI. Such efforts have been noted in the AT literature for youth and adult populations (Allen-Newman & Flemming, 2004;

Gilbert, Gilsdorf, & Ringer, 2004).

Finally, recognition for the importance of having preferred stories acknowledged brings up issues regarding instances of *anosognosia* or lack of awareness following ABI. As Lorent, Peeters, and Debaenst (2004) attest, anosognosia, often a characteristic of ABI, involves a general lack of awareness of the extent of injury and is associated with different behavioural symptoms (for example, communication problems regarding issues surrounding functionality and difficulties dealing with confrontation). For many ABI survivors, incongruity exists between how they see themselves versus how others see them, and as such, a goal of many rehabilitation therapists is to correct these dissonances. However, the current research suggests that multiple truths are possible depending on the narratives being used to interpret the situation. Therefore, practitioners who are interested in supporting reconstruction processes following brain injury are encouraged to be sensitive to the stories that their clients are relating and to not dismiss them frivolously. Rather, raising questions pertaining to whose interests are driving quests for “truth” is necessary, as is focusing on the narratives that prevent the realization of preferred stories. This entails an ethic of respect for the preferred stories that clients are striving toward and promotes curious and collaborative conversations that lead to shared understanding within the nexus where survivors exist.

Nature and Adventure: Important allies in the discovery of alternate narrative possibilities

Apparent in the three stories presented was the importance of nature and adventure in the construction of preferred narrative identities. In particular, recognition was apparent for how these experiences facilitated a disruption of the dominant identity conclusions that were threatening to box in and limit alternate possibilities in the

aftermath of injury. Evidently, had the program occurred in an indoor space and not involved adventure activities, the experiences of the participants would have been dramatically different.

The benefits of contact with nature and adventure activities in facilitating positive change have garnered considerable attention in the AT literature (e.g., Taylor et al. 2010) and beyond (e.g., Drengson, 2010). Thus, the author hopes this reflection will contribute to this literature by discussing how spending time in nature and engaging in adventure activities has contributed to the construction of preferred identities for Todd, Robert, and Diane.

Nature.

Todd's story contained the most explicit and lengthy conversation surrounding nature, so this reflection will commence by revisiting his story. For Todd, experiences in nature seemed to shift him away from the familiar binaries of progress vs. inertia and ablebodied vs. disabled. He described experiencing freedom, peace, and an absence of anxiety. From a narrative perspective, for Todd, being in nature seemed to facilitate the removal of constructions of separateness and failure encountered in his day-to-day life and instead provided meta narratives of connection and wholeness. Nature was experienced as an *unencumbered space*, a creative and healing context unfettered by the common threats to his preferred identity. Thus, being in a natural environment facilitated a distancing from the narratives that were defining Todd in limiting ways and created spaciousness through an expansion of his narrative possibilities.

As Todd explained, his early life experiences in nature were immensely positive and contributed to his interest in and strong relationship with nature in later life. This idea

of positive childhood experiences in nature contributing to a connection with nature in later years is supported in the literature, notably as documented in the work of Richard Louv (2005).

Conceptions of nature as a place of respite, peace, and opportune for development were shared by Robert and Diane. As a result, when immersed in nature they were also afforded opportunities for profound positive shifts in their identity.

Robert explained that being in nature allowed for moments of “fun“, an experience he believes is universal when in nature:

Well I’ve always loved fresh air. And I’m not the only person who feels that way, I know. Rather, I’m one of the six billion who loves fresh air and being out in nature, so being in an environment that I love makes it way easy to have fun.

Robert is suggesting that he too has always had a strong connection to the natural world. Further, this account points to how being in a natural environment he is passionate about provided opportunities to enjoy his life, as opposed to being reminded of his challenges. Similar to Todd’s experience, this account suggests that while in nature, the narratives available for Robert shift away from the dominant stories threatening his preferred identity and instead allow him to let go and experience freedom, joy, and “fun”.

Diane’s experiences in nature also involved states of peace and calm. Nature is a place that she “has always gone to” and that she “feels really comfortable with”. She also claimed that having her son out playing in nature supported her identity as a “good mother”, as she views such experiences as critical for healthy development. Thus, interactions with nature were potent antidotes to her chaotic life described outside the program.

A considerable and growing body of literature exists regarding the benefits of human-nature connections for human health and development (Frumkin & Louv, 2009; Khan & Kellert, 2002; Maller, Townsend, Pryor, Brown, & Leger, 2006).

The recent work of Maller et al. (2006) presents a literature review recounting the numerous human health benefits resulting from contact with nature. They describe the impressive body of anecdotal, theoretical, and empirical evidence supporting how both viewing and spending time in natural environments is associated with increased health and well-being. For example, citing the work of Furnass (1979), these authors highlight how experiences in nature have been shown to strengthen the activities of the right hemisphere of the brain, which they claim “is a technical explanation of the processes that occurs when people ‘clear their head’ by going for a walk in natural settings” (p. 50). Further, the work of Kaplan and Kaplan (1989), Ulrich (1984) and Parsons (1991) are all cited by Maller et al. (2006) to help explain how contact with nature can be restorative and enhance one’s ability to cope with and recover from stress and illness. In light of this broad literature base, they suggest nature “can be seen therefore as an under-utilized public resource in terms of human health and well-being, with the use of parks and natural areas offering a potential gold mine for population health promotion” (p. 52).

Evident in all three participant stories are experiences that resonate with the work presented by Maller et al. (2006). Moments of escaping from their problems, feeling free and rejuvenated, as well as experiencing an increased sense of well-being were noted. However, a narrative perspective was introduced to illuminate these experiences and provided an important additional dimension in understanding how previous constructions

of nature and spending time in natural environments contributes to human well-being, in particular the (re)construction of preferred identities.

In addition, recognizing the co-constructive basis of narrative identities, practitioners' own relationship with nature cannot be ignored. Practitioners in the MFP experience shared similar conceptions of nature and therefore supported and encouraged a view of nature as a place of healing and interconnection. Had their relationship with nature been one of fear or disinterest, undoubtedly the experiences of Todd, Robert, and Diane would have been quite different.

Numerous questions for further inquiry are apparent. For example, how do practitioners' relationships with the natural world influence participants' narrative identities while spending time outdoors? Would promoting strong connections with nature for survivors allow preferred identities to be more readily accessed? What would experiences in nature entail for survivors who do not have strong relationships with the natural world? How does one strengthen human-nature connections or a sense of ecological identity and what are the benefits for survivors of ABI in doing so? Finally, in light of the findings of Maller et al. (2006), how might the benefits of contact with nature in the context of traditional ABI rehabilitation approaches be best utilized?

Considerable ground has been covered in exploring some of these questions, such as how to enhance human-nature connections and what the benefits may be of encouraging the development of ecological identities (e.g., Macy & Brown, 1998; Naess, 1987). As for the remaining questions, much work remains.

Adventure.

With regard to adventure activities, evident in all participants' accounts were the shifts in identity that were noted in descriptions of their involvement in adventure

activities such as the challenge course, climbing wall, hiking, and sea kayaking. Importantly, none of their accounts involved significant descriptions of misadventures, or experiences where they felt physically or emotionally harmed as a result of their involvement in any activity. The effective management of risk in adventure activities is a critical component of facilitating AT experiences (Harper & Robinson, 2005), and thus *adventure activities* refers more to the experience of adventure versus the actual presence of risk.

As described in Diane's story, opportunities to challenge herself through adventure activities and subsequently successfully navigate through those situations contributed to her identity as a "strong person" who is more aware of her abilities to make it through her situation. Through certain individualized lenses, this experience could be theorized as enhancing her self-esteem and increasing her internal resiliency. From a narrative perspective, however, Diane's experiences during the challenge components of the MFP facilitated the possibility for her to access preferred narratives of strength and perseverance that were restricted by her life beyond the program. Further, having practitioners present to provide the adventure experiences and a social group to witness her successes were noted as key components of this experience for many of the reasons discussed in the social context section above.

Similar experiences were noted by Todd and Robert; yet, a significant area of difference lies in how being present for others and having themselves attended to during adventure activities were critical components of their experience. Todd's story contains an inherent tension. He claimed that viewing the other brain injured survivors engage in challenge activities either supported his relationship with hope or contributed to a sense

of discomfort. When he was able to view other people overcoming their physical barriers and “succeeding” this supported his own story of hope and success. But when his peers encountered difficulties due to their physical limitations, this was a frightening reminder of his story of limitation and served instead to threaten his relationship with hope. Lorent et al. (2004) discuss the potential for adventure activities, in the service of ABI survivors, to bring to light their limitations, sometimes contributing to increases in anxiety and discomfort. Todd’s story certainly supports these findings. As for Robert, his experiences of success in the adventure elements facilitated opportunities for him to be viewed as a “competent strong man”, and this served to challenge his diminished status. Further, he explained how wonderful it was to have a “good night sleep” following being outside and getting “vigorous exercise”. Robert was sure to make clear that this good night sleep was not because he was a fatigued brain injured man, but instead due to the fact that he had worked hard and “justly earned it”. Thus, for Robert, engaging in adventure activities facilitated shifts towards his preferred identity of being authentic and undiminished.

These points resonate with the work of the late narrative therapist Michael White (2007), where he relates Vygostky’s (1986) learning and development theory to narrative shifts made in therapy. White (2007) explains how Vygotsky’s theory of learning and development includes social collaboration as a key component of development, and that developmental ends are best rendered through the carefully sculpted introduction of new challenges, said to be within the person’s “proximal zone of development” (as cited in White, 2007, p. 275). Therefore, according to White (2007), reauthoring processes need to be “scaffolded” (p. 275) by caring collaborators, such that incremental and progressive movements across the proximal zone of development can occur.

These parameters were certainly evident in the adventure experiences related by Todd, Robert, and Diane. Specifically, the adventure activities occurred within a supportive social context, staged by trained practitioners, and could be said to have contributed to the participants' experiences of being in their own proximal zone of identity development.

Again, these reflections raise numerous issues regarding adventure and identity in the context of ABI. Curiosity looms regarding how practitioners can ensure the appropriate scaffolding of adventure experiences, such that positive shifts in identity are rendered possible. Further, attention towards minimizing the perpetuation and support of problem-saturated stories is an important area of concern, in light of Todd's story. Clearly, as is the case with nature, adventure activities have a promising role in the reclamation of preferred identities following ABI.

The importance of hope in the construction of narrative identity following injury

The final area of interest in the stories of Todd, Robert, and Diane is the importance of hope in their post-injury identities. Their stories highlight the diversity of relationships that exist with hope in the recovery process and how particular narratives contribute to these differences. Further, they suggest that hope following injury is dynamic and multilayered versus static and unified.

Todd's story demonstrates how a restitution narrative contributes to a particular relationship with hope, serving as a vital ally in his journey towards recovery. Hope is central in narratives of his previous self and progressing towards achieving a positive outcome. Thus, events that support this focus, such as news of medical advancements or improvements in functioning, are highly regarded. Likewise, conflicting knowledge or

events, as seen with his counsellor or in moments of struggling to do the tasks he used to do easily, have the potential to quickly lead to frustration and despair.

Robert's quest narrative serves to create a different relationship with hope, one in which hope is not centred on his physical recovery or progress, but rather is more open to the unfolding of his life, and as he states "proving his doubters wrong". His experience of wholeness in the coma state and finding meaning in his injury allowed for a broader definition of hope, seemingly resulting in more possibilities to defy despair when compared to Todd.

Finally, Diane's story contains significant shifts in her relationship with hope. In the early years of her husband's accident, Diane describes being hopeful that her life could return to its pre-accident form. This resembles the restitution narrative, a similar form of hope as seen with Todd. Also evident is how this narrative structure facilitated a loss of her own preferred identity, an important contribution to understanding the phenomenon of caregiver identity disruptions. Through the course of her involvement in the MFP and subsequent reclaiming of her preferred narratives, hope shifted away from her husband's recovery and towards both her own and her son's well-being.

These findings support the conclusions of Smith and Sparkes (2004) surrounding the power of self-narratives following injury to "shape experience in general, and the kinds of hope used in personal accounts in particular" (p. 1102). Further, they bring to light the importance of hope in human change processes (Mahoney, 2003) and particularly how relationships with hope are intimately connected to relationships with despair (Jenmorri, 2006).

Jenmorri's (2006) research highlights how particular relationships with hope and

despair can limit the potential for resilience and sustainability in the face of difficulty. Although her research was focused on therapists working with survivors of trauma, her insights are helpful in the context of this discussion. In particular, her suggestions that when hope is constructed around a specific future outcome (e.g., recovery) then moments of stagnation are more likely to bring forth experiences of despair due to the creation of a binary of good (movement) and bad (stuckness). This was certainly the case with Todd and for Diane during the early experiences of her husband's recovery. Jenmorii (2006) suggests that if hope and despair can be re-imagined as interrelated possibilities in which moments of despair are seen as "a useful moment in a wider process of change, a time for reconnecting to life and meaning making" (p. 99), then this can promote growth and sustainability in the face of adversity.

Relating these insights to the current study brings up questions pertaining to the survivors' different relationships with hope and how these come to influence experiences of recovery. How would Todd's experience of recovery be different if his relationship with hope was not bound so tightly with progress? Do particular relationships with hope facilitate the reconstruction of preferred identities more easily than others? What are the processes by which survivors are drawn to different narratives of recovery and hope? How do shifts in relating to hope occur, such as in the case of Diane? Finally, if therapists are the socially sanctioned holders of hope (Mahoney, 2003), does this require privileging particular types of hope over others in light of Jenmorii's (2006) findings?

Clearly, hope in the aftermath of acquired brain injury is an important concept worthy of further investigation. Researchers and practitioners interested in the area of supporting survivors are encouraged to seriously consider narratives of hope as a crucial

component of narrative identity post-injury.

Limitations of this study

This research is a highly localized qualitative investigation of a select number of participants from a unique outdoor adventure program. Inherently, this entails limitations worthy of mention.

First, by selecting only three adult participants, the diversity of experiences represented from the program and the ABI community was restricted. In particular, the voices of the children and survivors who struggle to communicate verbally are absent. As noted, the decision to include three adult participants was a balance between what was practically possible given the storied nature of this research, as well as methodological considerations associated with including children, youth, and adult participants who were not able to articulate their experiences verbally. The numerous benefits of including multiple voices are recognized, as is the need to investigate methodologies that can adequately address the linguistic barriers associated with ABI, particularly in narrative inquiries.

Second, the small sample size and narrative constructionist methodology resulted in a highly specific and particular analysis of life following ABI, limiting alternate interpretations of participant stories. As articulated in the methodology section, this research focused on creating contextual accounts of life following ABI and was therefore not intended to be generalized or viewed as the *Truth*. Rather, it was intended to illuminate the shifts in narrative identity of the participants and to generate discussion regarding further areas of inquiry and implications for practice.

Finally, this research focused on survivors who participated in a unique program being offered in the Victoria area. Due to the fact that outdoor adventure programs in the context of ABI rehabilitation are extremely rare, these results may appear to not be as relevant to the everyday practitioner or survivor had the focus been on more traditional office-based approaches. However, recognition for the multiplicity of identities and particularly the need for practitioners to assist survivors in opening up alternate narrative possibilities does not require an outdoor adventure approach. Rather, it entails conceptualizing the self through a particular lens, one that can accompany a practitioner in the numerous contexts they inhabit. Incorporation of a outdoor adventure program undoubtedly supported this process.

Concluding remarks

This research investigated the shifts in narrative identity of Todd, Robert, and Diane following their involvement in a unique multi-family outdoor adventure program. In doing so, the relational processes involved in identity formation as well as the potential for creating opportunities for alternate and preferred stories has been illuminated. Further, this work brought attention to the influence of social contexts, nature and adventure, and relationships with hope as areas of importance and warranting of additional research.

Unfortunately, many survivors continue to struggle to reclaim, rediscover, and reconstruct their preferred identity in the aftermath of their injuries. Thus, this thesis hopes to inspire additional research and practice in the area of identity reconstruction following injury in general, and in the promising area of multi-family outdoor adventure programs in particular.

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Appendix A Description of the Program

The Acquired Brain Injury Multi-Family Outdoor Adventure Program (MFP)

For the past four years I have been involved as a practitioner in a unique Adventure Therapy (AT) program that seeks to serve people who are experiencing the impacts of an acquired brain injury. As mentioned in the literature review, this population is seriously underserved regarding addressing psych-social concerns (e.g., intimate relationships, family, community involvement). This is definitely the case in the greater Victoria area where a large number of people who have sustained a head injury are not receiving professional services (either due to long wait-lists, lack of programs, or a lack of awareness of any injury (personal communication, Barbara Erickson, Victoria Brain Injury Society, August 16, 2009). In particular, there is a serious lack of service provisions for individuals once they leave in-patient rehabilitation and extremely limited service options for children and caregivers of those who have been injured (personal communication, Barbara Erickson, Victoria Brain Injury Society, August 16, 2009).

Recognizing the need in the ABI community for an increase in services that specifically addressed family and community needs, Marie Hendrix, a former family counsellor with the Victoria Brain Injury Society (VBIS, previously known as the Vancouver Island Head Injury Society) launched a multi-family outdoor adventure therapy program in collaboration with Power To Be Adventure Therapy Society. This project, initially funded through the Rick Hansen Foundation, aimed to support participants in strengthening relationships with themselves, with their family members, and within their broader community of support.

A collaborative community approach was utilized in the design of the program, whereby the VBIS managed referrals and intake, monthly family psycho-education and counselling sessions, and diversity training with regards to ABI for program volunteers and Power To Be staff. Moreover, Power To Be designed and implemented a three-phased outdoor experiential curriculum that spanned an 8-month period. The first phase was a two-day weekend experience focusing on relationship building and goal setting. The second phase spanned 6 months and included monthly adventure days centered on a relevant theme (e.g., trust in the family, discovering new potentials, dealing with conflict, etc.). Specific activities included:

- sea-kayaking;
- rock-climbing and low ropes elements;
- individual, family and group experiential activities,
- spending time in nature (walking, sitting)
- service learning projects
- sharing nutritious food together.

The program completed with a weekend camping trip. Additionally, the adults in the program met once per month with the VBIS counsellor to explore common problems and gain support from one another. The adventure days took place at local parks and community organizations so families could gain familiarity with these outdoor recreational resources for their future enjoyment.

Initially, a collaborative team from both Power To Be, VBIS, and a group of dedicated volunteers, ran the program. In the first year, four families signed up and completed the program. Responses from participants were extremely positive, and the program was extended and is currently serving five families (four of which are the original participants), although in a slightly different capacity. The goals and structure of the program have not changed, with the exception of the adults not all meeting together for their monthly evening counselling sessions. Instead, the evening group sessions have been separated based on clients' relationship to the injury (caregiver, person with the injury, child). In addition, as a result of their familiarity with the program and people involved, many of the families have taken on more of an active role in designing the adventure days. Finally, the VBIS is no longer a direct partner with Power To Be in the delivery of the program, but rather a valuable referral destination.



Appendix B Informed Consent Form

Participant Consent Form

Examining Experiences and Impacts on Family Functioning Following Acquired Brain Injury

You are being invited to participate in a study entitled “*Examining Experiences and Impacts on Family Functioning Following Acquired Brain Injury*” that is being conducted by David Segal, MA CYC Candidate.

Background Information

David Segal is a Graduate Student in the Faculty of Human and Social Development’s School of Child and Youth Care at the University of Victoria and you may contact him if you have further questions by email at dsegal@uvic.ca or by phone at (250) 588-7214.

As a graduate student, I am required to conduct research as part of the requirements for a degree in Child and Youth Care. My research is being conducted under the supervision of Dr Marie Hoskins. You may contact my supervisor by email at mhoskins@uvic.ca or by phone at (250) 721-7982.

Additional people involved in the research are:

Supervisor Nevin Harper: njharper@uvic.ca

Community Partner: Tim Cormode, Executive Director of Power to Be Adventure Therapy Society: tim@powertobe.ca

Purpose of Research

The purpose of this research is to learn more about the experiences of survivors of acquired brain injury (ABI) and their families. We also want to learn about the impact that these experiences have on family functioning. Finally, we are interested in learning about how families’ involvement in Power to Be’s family nature and recreation program has impacted family functioning.

Importance of Research

Research of this type is important because it can help professionals in treatment and recovery services to better understand, and therefore better serve, the challenges and needs of families who have experienced ABI. It can also help to improve the Power to Be ABI Family program to better serve families in the future.

Participants Selection

You are being asked to participate in this research because you have either participated in Power to Be’s ABI family program and/or because you are part of a family who has experienced an ABI. Our focus will be on the ABI survivor and their primary caregiver in the family.

What is Involved

If you agree to voluntarily participate in this research, your participation will include two one-hour, one-on-one interviews with one of our researchers. This interview will take place at the University

of Victoria. Individual interviews will be conducted with both the ABI survivor and their primary family caregiver.

Inconvenience

Participation in this study may cause some inconvenience to you in terms of the time you take from your busy schedule to participate and your transportation to and from the interviews.

Risks

There are some potential emotional risks to you by participating in this research. These include: Embarrassment, fatigue, stress, emotional discomfort, or the possible surfacing of family dynamics that might not have otherwise surfaced. In order to minimize these emotional experiences, the researcher will try to create a safe, supportive environment similar to that of a counseling session. There will be no pressure to continue in the research if you decide to withdraw. You will also be invited to take a break at any time during the interview if you feel you need to do so. Finally, the interviews will be followed by a debriefing session in which you will be given the opportunity to discuss anything that feels unresolved. If at any time after the interview, you feel you need to debrief anything, feel free to contact the researcher. If necessary, the researcher can refer you to the professional counseling services offered at the Victoria Brain Injury Society for individuals and families living with acquired brain injury.

Benefits

The potential benefits of your participation in this research include: An improved understanding for you and your family of the experience of ABI and its impact on your family; the improvement of services available to you and to other families who have experienced ABI; and the beginning of more research done on the experience of loss and impact on family functioning following ABI.

Compensation

As a way to compensate you for any inconvenience related to your participation, you will be given a \$30 honorarium. The first \$15 of this will be awarded to you following the completion of your first interview, and the remaining \$15 following the completion of your second interview. If you agree to participate in this study, this compensation to you must not be coercive. It is unethical to provide undue compensation or inducements to research participants. In other words, if you would not participate if the compensation was not offered, then you should decline.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study you will be asked whether your anonymous data can be used and analyzed. If you decline this option, your data will not be used and will be destroyed. If you withdraw before the first interview, no compensation will be granted to you. If you withdraw after the first interview you will still receive your \$15 compensation; if you withdraw after the second interview you will still receive the full \$30 compensation.

Researcher's Relationship with Participants

The researcher may have relationship to potential participants as a previous facilitator in the Power to Be ABI family program in which families in this study may have participated. To help prevent this relationship from influencing your decision to participate, the researchers will ensure there is an understanding that participation in, or withdrawal from, this study will not influence future enrolment in Power to Be's programs. Additionally, strict confidentiality of your personal information and experiences shared through the research will be respected and this information will not be used outside of the study.

Ongoing Consent

To make sure that there is continued consent and understanding throughout the study, a copy of this consent form will be given to you to read and sign before both the first and second interviews.

Anonymity

Your anonymity will be protected before, during, and after your participation in this study. If you choose to not participate at any time, your anonymity will still be protected. This will be done by putting numbers instead of names on the interview transcripts and referring to the numbers when analyzing and commenting on the transcripts. This will help minimize the risk that anyone will be able to associate your data (interview transcripts in this case) with you. For those participants who were enrolled in the 10 month Power To Be program, due to the small number of people in the program and the uniqueness of the program (only one of it's kind in Canada), there is a risk of personal identification despite the measures taken to maintain anonymity.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by not using any identifying information attached to the data. The consent forms and interview transcripts will be kept separately from each other (i.e. not attached to one another). Hard copies of the interview transcripts will be kept in a locked file. Digital recordings and accompanying analysis will be kept on the principle investigators password protected personal laptop. For those involved in the Power To Be program, as mentioned above, there is a risk of personal identification and thus your complete confidentiality regarding your involvement in this study cannot be guaranteed.

Dissemination of Results

The results of this research will be distributed in the following ways: Thesis and class presentation; presentations to scholarly meetings; published article or chapter; and directly to the participants as well as Power To Be in the form of an executive summary.

Disposal of Data

The data collected in this study will be destroyed five years after the completion of the study. The hard copy will be shredded and the digital copy will be removed from the computer's hard drive.

Contacts

Individuals that may be contacted regarding this study include:

David Segal: dsegal@uvic.ca or (250) 588-7214

Marie Hoskins: mhoskins@uvic.ca or (250) 721-7982

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study and you have had the opportunity to have your questions answered by the researchers.

Printed Name of Participant

Signature

Date

Appendix C Epistemological Differences

The Differences Between Conventional and Reformist Research in the Social Sciences.

Conventional

Reformist

Truth <i>What is truth?</i>	Absolute Truth exists and is accessible through employment of the scientific method.	No capital 'T' ruth exists. Rather, truth is partial, contextual and relational.
Reality <i>What is real?</i>	Objective reality exists and is external from individual and cultural influence. (Kvale, 1996)	Reality is intersubjective, co-constructed and multiple. (Gergen, 1999)
The Subject <i>What constitutes the subject?</i>	Humanist Self: Autonomous, separate, rational, agentic, and consistent. (Davies, 2000)	Narrative Self: Relational, fragmented, multiple, variable and context-specific. (Davies, 2000; Gergen, 1991)
Validity of Knowledge Claim <i>What counts as evidence?</i>	Derived through numerical scores and statistical procedures. Interested in cause and effect relationships. Controls for extraneous variables and uses randomized control trials. (Polkinghorne, 2007)	Requires evidence in the form of personally reflective descriptions in ordinary language and analysis using inductive processes. (Polkinghorne, 2007)
Interpretation of Results <i>What is done with the results?</i>	Research offers explanations of the implications of results and hopes to generalize to larger population. (Polkinghorne, 2007)	Research develops implications by comparing and contrasting with other relevant accounts on similar topics. Contextual accounts that are not intended to be generalizable. (Polkinghorne, 2007)
The Researcher <i>What is the influence of the researcher?</i>	Value-neutral, able to stand outside of the research process. (Polkinghorne, 2007)	Value-laden, not able to be separated from their own historical and cultural embeddings. (Polkinghorne, 2007)
Evaluating Evidence <i>How are the research findings evaluated?</i>	Research methodology screened for adherence to scientific method. Statistical analysis produces gradations of the limits of confidence. (Polkinghorne, 2007)	Readers asked to make judgments on whether or not the evidence and argument convinces them at the level of plausibility, credibility, or trustworthiness of the claim. (Polkinghorne, 2007)
Unit of Analysis <i>What is being analyzed?</i>	Individuals and/or groups scores on tests, or content of interviews. (Polkinghorne, 2005)	Human experience accessed through discourses, narratives, subjective accounts (Polkinghorne, 2005)
Theorems and Theories <i>What is considered sound theory?</i>	Logical, reductive, parsimonious, elegant. (Lincoln, 2010)	Those that strive to answer 'why', are a-rational, and derived from pure lived experience. Theories described as thick and complex. (Lincoln, 2010)
Control <i>What role does control serve in research?</i>	Controls are put in place to filter alternate ways of knowing and encourage rational knowing. (Hoskins, 2001)	Control used in the way of influencing the mind to stay open to multiple sensory modes of knowing. (Hoskins, 2001)
Rules for scientific research <i>How explicit are research procedures?</i>	Explicit and well-established. Little variation tolerated. (Hoskins, 2001)	No set rules. Instead epistemological and ontological articulation and congruence is strived for. (Hoskins, 2001)
Participant Selection <i>How are participants selected?</i>	Randomly selected from general population. The larger the sample size the more robust the study. (Polkinghorne, 2005)	Purposive sample. Participants chosen for closeness to the experience of interest. (Polkinghorne, 2005)

*All citations are included in the references section above

Appendix D Ethics Approval



Human Research Ethics Board
Office of Research Services
University of Victoria
Administrative Services Building - 2nd Floor
Tel (250) 472-4545 Fax (250) 721-8900
Email ethics@uvic.ca Web www.research.uvic.ca

Human Research Ethics Board Certificate of Renewed Approval

<u>Principal Investigator</u> David Segal Master's Student	<u>Department/School</u> CHIL	<u>Supervisor</u> Marie Hoskins
<u>Co-Investigator(s):</u> Dr. Marie Hoskins, Graduate Supervisor, UVic Dr. Nevin Harper, Co-Investigator, UVic Tim Comoda, Community Partner, Power To Be		
<u>Project Title:</u> Examining experiences and impacts on family functioning following acquired brain injury		
<u>Protocol No.</u> 09-075	<u>Original Approval Date</u> 10-Mar-09	<u>Renewed On</u> 05-Mar-10
		<u>Must Renew By</u> 09-Mar-11

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

This Certificate of Approval is valid for the above term provided there is no change in the protocol. Extensions and/or amendments may be approved with the submission of a Request for Annual Renewal or Modification form.

Dr. Atzal Suleman
Associate Vice-President, Research

09-075 Segal, David

Appendix E Power To Be Letter of Support

Letter of Support from Power To Be Adventure Therapy Society

To whom it may concern,

This letter signifies Power To Be's agreement to support the research study being conducted by David Segal, titled *Examining Experiences and Impacts on Family Functioning following Acquired Brain Injury.* Specifically, Power To Be agrees to contact past participants from the ABI family program and inform them of their voluntary opportunity to take part in the study. This will be done through email and will contain an attachment of the recruitment poster created by the researchers.

If you have any questions, please do not hesitate to call.

Sincerely,

Tim Cormode

Executive Director and Founder

Appendix F Recruitment Letter Sent by Power To Be

Hello Everyone,

I have been asked to send out information detailing the study we mentioned at our last meeting. I have attached it below. Please contact Dave Segal if you are interested in participating or have any questions. He can be reached at 250 588 7214 or at dsegal@uvic.ca. Please note you are under no obligation to participate in the study and that your decision will in no way impact the services you are receiving or may receive from Power To Be.

Kind regards,

Carinna Kennigsberg

Researchers from the University of Victoria are currently seeking participants for their unique study entitled, **Examining experiences and impacts on family functioning following acquired brain**, funded by the Disability Health Research Network.

You are being asked to participate because you were involved in the Power To Be ABI multi-family nature program and we are interested in learning more about your experiences.

If you chose to participate, you and your current or past partner will meet separately with a research assistant for two one-hour interviews, approximately two weeks apart. These interviews will be held at the University of Victoria or your home. You would each be granted \$30 (\$15 for each interview) to compensate you for taking the time to meet with us.

Your participation would be completely voluntary, meaning you could withdraw at any time. All of your information would also be kept confidential and no identifying information would be connected to your interview transcripts or to any published results from the study. David Segal's role as a research assistant is separate from his previous role as a facilitator of Power To Be's programs, and your decision to participate in this study will not impact your ability to access future Power To Be services.

If you are interested in participating and/or would like more information, please contact David Segal at dsegal@uvic.ca or by phone at 250 588 7214

Appendix G Recruitment Script

Recruitment Script for Past Power To Be ABI Family Program Participants

Researcher (R): Hello, _____ speaking.

Family Member (FM): Hi, I'm calling about the letter I got from Power To Be looking for people to participate in a research study.

R: Great. Thanks for calling. Did you have some questions about it?

FM: Well, what is it you're doing exactly?

R: We would basically be exploring with you some of your experiences of dealing with an acquired brain injury in your family, and how that has impacted your family. We are also interested in learning from your experiences with Power To Be's family program that you did, how this program and others like it might be improved. Is this something you think you might be interested in participating in?

FM: Sure. So what would I have to do?

R: If you chose to participate, you and your spouse would each meet with me or my research assistant for two individual one-hour interviews, two weeks apart. These interviews would be held at the University of Victoria. You would each be granted \$30 (\$15 for each interview) to compensate you for taking the time to meet with us.

FM: okay...

R: And your participation would be completely voluntary, meaning you could withdraw at any time. All of your information would also be kept confidential and no identifying information would be connected to your interview transcripts or to any published results from the study. My role as a researcher is separate from my role as a facilitator of Power To Be's programs, and your decision to participate in this study will not impact your ability to access future Power To Be services.

FM: Can I talk to my [spouse] and get back to you?

R: Sure. No problem. You can contact me by phone at _____, or by email at _____ . And we would like to know by _____.

OR:

FM: Okay, I know I would be interested, and I will have to check with my [spouse]. When would the interviews be held?

R: Really, whenever works best for you. We would like to start by _____. Is there a day in there that might work for you and [spouse's name]? Keep in mind that you would need to be able to schedule your second interviews for 2 weeks after the first ones.

FM: Okay, how about _____ and _____.

R: Sounds perfect. And the interviews will be held at the University. I will book a room up there and let you know the exact location. If you need to contact me in the meantime, let me leave you my contact information.

FM: Okay.

R: My phone number is _____. And my email address is: _____. And what is your name?

FM: [gives name]

R: And in case we need to contact you beforehand, what is your phone number?

FM: [gives phone number]

R: [FM Name], thank you for your interest. Your participation means a lot to this study, and I hope it will also be valuable for you. Please don't hesitate to contact me if you have any concerns or questions or if anything changes. And I will see you at ___[time]_ on ___[date]___ at the University of Victoria, and again on ___[date]___ at ___[time]___.

FM: okay

R: Thanks again, talk to you soon.